MEMORANDUM

To: SCPD Policy & Law Committee

From: Brian J. Hartman

Re: Regulatory Initiatives

Date: October 10, 2016

Consistent with the requests of the SCPD and GACEC, I am providing analyses of twelve (12) regulatory initiatives in anticipation of the October 13 meeting. Given time constraints, the analyses should be considered preliminary and non-exhaustive. DHSS also published in the Register a solicitation of comments on updates to the Delaware Statewide Transition Plan by November 18, 2016 [20 DE Reg. 314 (10/1/16)]. Given the scope of the relevant documents, I lacked the time to prepare an analysis.

1. DMMA Final ABLE Act Regulation [20 DE Reg. 283 (10/1/16)]

   The SCPD and GACEC commented on the proposed version of this regulation in May, 2016. The SCPD’s comments and DMMA’s response are included in the attached August 16, 2016 DMMA memo. The memo “mirrors” the DMMA analysis in the published regulation, 20 DE Reg. at 285-287.

   First, the Councils recommended amending the definition of “person with signature authority” to clarify that a competent individual could simply opt to not exercise signature authority. The Division agreed and adopted a conforming revision.

   Second, the Councils recommended the addition of “consortium of states” in the definition of “ABLE program”. The Division agreed and adopted suggested language verbatim.

   Third, the Councils recommended expanding the definition of “eligible individual” to include persons participating in a consortium arrangement. DMMA expanded the definition to include residents of all states in which an ABLE program is established.

   Fourth, the Councils recommended adding a reference to “consortium ABLE program”. DMMA agreed and adopted suggested language verbatim.
Fifth, the Councils recommended reconsideration of a residency requirement. DMMA noted that its amended definition of “eligible individual” expanded eligibility to a resident of any state in which an ABLE program is established.

Sixth, the Councils identified a grammatical error. DMMA corrected the reference.

Seventh, the Councils identified a grammatical error. DMMA corrected the reference.

Eighth, the Councils questioned the less favorable treatment of distributions for housing. The Division responded that the approach was based on SSI policy which treats distributions for housing expenses differently than distributions for other expenses.

Since the regulation is final, and DMMA adopted several amendments based on Council commentary, a “thank you” communication should be considered.

2. DMMA Final Autism Services Regulation [20 DE Reg. 291 (10/1/16)]

The SCPD and GACEC commented on the initial version of this proposed regulation in April, 2016. The Division of Medicaid & Medical Assistance then published a revised proposed regulation in July which incorporated some amendments prompted by the Councils’ commentary. The Councils submitted three (3) comments on the July version of the proposed regulation. The attached August 19 DMMA memo summarizes the latest comments and the Division’s response. The memo “mirrors” the DMMA analysis in the published regulation, 20 DE Reg. at 293-295.

First, the Councils observed that substitution of “behavioral interventions” for “services to treat Autism Spectrum Disorder” was unduly limiting. In response, DMMA amended several references.

Second, the Councils objected to a provision conferring unilateral control over caregiver participation/implementation of the service plan to a “practitioner”. The Councils recommended adoption of a more collaborative sentence. The Division adopted the Council’s suggested sentence verbatim.

Third, the Councils identified a grammatical error which the Division corrected.

Since the regulation is final, and the Division adopted revisions based on each of the Councils comments, a “thank you” communication should be considered.

The SCPD and GACEC commented on the initial version of this proposed regulation in December, 2015. In June, 2016, the Department of Education published a revised proposed regulation incorporating some edits prompted by the Councils. The Councils submitted a lengthy set of thirty (30) comments on the revised proposed regulation. A copy of the GACEC’s June 27, 2016 letter is attached for facilitated reference. The DOE is now adopting a final regulation with some edits. Instead of publishing a summary of comments and its responses in the Register, the DOE indicates that it was sending letters to commenting agencies. At 278. Based on a GACEC inquiry, the DOE indicated that the letters would be sent out by October 7. As of morning of October 10, the GACEC had not received a letter. I am therefore constrained to summarize revisions based on information gleaned only from the Register. Here’s a brief analysis based on the 30 comments in the GACEC’s attached June 27, 2016 letter.

- Comments 1-2: No change.
- Comment 3: No change conforming to the comment but definition of “parent” was changed to add “or entity”.
- Comment 4: No change conforming to the comment but the definition of “building level conference” was changed to add “a student”.
- Comment 5: No change.
- Comment 6: DOE added “applicable to this regulation” to the definition of “grievance”.
- Comments 7-20: No change.
- Comment 21: DOE added a time period for the notice.
- Comment 22-30: No change.

The resulting regulation provide inadequate protections to students with disabilities and fails to fairly “balance” student vs. administrator interests.

4. DOE Proposed “Age of Majority” Regulation (Part 1) [20 DE Reg. 233 (10/1/16)]

The DLP, GACEC and other councils were highly involved with the drafting and enactment of State legislation (S.B. No. 180) implementing a federal regulation (34 C.F.R. 300. ) addressing educational decision-making upon a student’s attainment of age 18. The legislation, enacted in June, requires the DOE to promulgate implementing regulations in consultation with the GACEC. Representatives of the DLP, GACEC, DOE, and school districts reached consensus on regulatory text in September. The DOE is now formally publishing two (2) sets of regulations based on that consensus. This is the first set of proposed regulations.

This regulation revises a single sentence in an IEP regulation resulting in the following standard:

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20.3. Transfer of rights at age of majority: Beginning not later than one year before the child reaches the age of 18, the IEP shall include a statement that the child has been informed that the child’s rights under 14 Del.C. §3132 will transfer to the child, or an educational representative or educational surrogate parent on reaching the age of 18 under 14 DE Admin Code 926.20.0.

This recital is accurate and alerts IEP participants to the statutory and regulatory sections which provide detailed standards on decision-making upon the student’s attainment of age 18.

The Councils may wish to consider endorsement.

5. **DOE Proposed “Age of Majority” Regulation (Part 2) [20 DE Reg. 233 (10/1/16)]**

The DLP, GACEC and other councils were highly involved with the drafting and enactment of State legislation (S.B. No. 180) implementing a federal regulation (34 C.F.R. 300.) addressing educational decision-making upon a student’s attainment of age 18. The legislation, enacted in June, requires the DOE to promulgate implementing regulations in consultation with the GACEC. Representatives of the DLP, GACEC, DOE, and school districts reached consensus on regulatory text in September. The DOE is now formally publishing two (2) sets of regulations based on that consensus. This is the second set of proposed regulations.

This regulation essentially “tracks” the requirements of S.B. No. 180 while adding some supplemental “common sense” provisions. For example, if the IEP team determined that a student lacked capacity in a prior review, the participation of a school psychologist in later IEP meetings would be “discretionary if it is clear there has been no change in the child’s capacity.” See §20.1.3.1.

Parenthetically, the DOE has incorporated some “housekeeping” revisions in the regulation unrelated to S.B. No. 180. For example, the DOE includes some minor edits to §11.0 to conform to changes in the relevant statute, 14 Del.C. §3137. The DOE is also amending §4.0 to require the provision of a copy of procedural safeguards to the parents at each IEP meeting. This conforms with a regulation adopted last month, 20 DE Reg. 172 (9/1/16).

The Councils may wish to consider an endorsement subject to one important suggestion. At the federal level, the President’s Committee for People with Intellectual Disabilities issued an October 6, 2016 report which includes “Recommendation 55” encouraging the sharing of information about supported decision-making with families of IDEA transitioning students. See attachment. At the State level, the Governor signed S.B. No. 230 on September 15, 2016. That legislation authorizes competent adults to execute a “supported decision-making agreement”. It would be preferable for IEP teams to be aware of this option. For example, the new law specifically authorizes agents appointed through a supported decision-making agreement to assist with accessing educational records and assisting the principal (adult student) with educational decision-making. See, e.g., 16 Del.C. §§9403A(11)(h), 9406A(a)(2), and 9409A. Since the regulation (§20.1.2) already addresses powers of attorney and voluntary grants of authority, it makes sense to include a reference to supported decision-making in the same section. Consider adding the following bracketed second sentence to §20.1.2 as follows:
20.1.2. A child with a disability with capacity may authorize an adult agent to exercise rights through execution of a power of attorney or standard voluntary grant of authority form published by the Department of Education. [A child with a disability with capacity may also authorize an adult agent to provide assistance with making and communicating educational decisions through execution of a supported decision-making agreement authorized by 16 Del.C. Ch. 94A.]

In its discretion, the GACEC may wish to solicit an endorsement of this amendment from the prime sponsors of S.B. No. 180, Senator Poore and Rep. Heffernan, to share with the DOE.

6. DOE Prop. Medications & Treatments Reg. [20 DE Reg. 231 (10/1/16)]

The Department of Education is amending a regulation to conform to recent enactment of the attached S.B. No. 181. The legislation essentially authorizes a designated caregiver to administer medical marijuana oil to a minor in a preschool, school, or school bus.

I have the following observations.

First, the DOE revisions are limited to nonregulatory notes. I did not identify any significant concerns with the proposed revisions.

Second, there is some “tension” between S.B. No. 181 and disability-related laws. S.B. No. 181 categorically bars a school nurse, employee or contractor from serving as a designated caregiver for the purpose of administering prescribed medical marijuana oil. In contrast, schools are required to accommodate the needs of students with disabilities under the ADA, Section 504, and the IDEA. In the medication context, public schools have been required to administer insulin, epinephrine, and other drugs. See, e.g., Region IX OCR LOF to Conejo Valley (CA) Unified School District, 20 IDELR 1276 (October 27, 1993) [district violated Section 504 by declining to establish an appropriate emergency response system for insulin-dependent child and disallowing trained laypersons to administer injections]; and Region III OCR LOF to Berlin Brothersvalley (PA) School District, 14 IDELR 353: 124, 125 (December 23, 1988) [district violated Section 504 by requiring parent to sign waiver of liability as precondition of administration of allergy medication]. Cf. Cedar Rapids School District v. Garrett, 526 U.S. 66 (1999) [adopting broad view of school responsibility to provide school health services to students with disabilities]. Administration of medications is a type of school health service. See 34 C.F.R. 300.34. Thus, if an IEP team determined that administration of prescribed marijuana oil were necessary to permit a student to attend school and receive a FAPE, the school would be responsible for implementing/facilitating that determination. At a minimum, the DOE may wish to include a non-regulatory note:

For students with disabilities, limitations on administration of medications are subject to exceptions based on the Americans with Disabilities Act, Section 504, and the IDEA, including a duty to provide school health services and health-related accommodations.

The Councils may wish to share the above observations with the Department and SBE with a courtesy copy to the Attorney General.
7. DOE Prop. Poss., Use or Dist. of Drugs/Alcohol Reg. [20 DE Reg. 223 (10/1/16)].

The Department of Education is proposing to adopt a set of amendments to its regulation covering possession, use and distribution of drugs and alcohol.

I have the following observations.

First, §1.0 merits reconsideration. The current preface to the regulation contemplates public schools complying with its terms. The proposed change would make the terms “minimums” from which public schools could vary:

The purpose of this regulation is to outline the minimum requirements to be included in all public school district and charter school policies on the Possession, Use, or Distribution of Drugs and Alcohol.

[emphasis supplied]

This approach is at odds with legislation directing the DOE to adopt “uniform” definitions of student conduct subject to discipline and “uniform” disciplinary due process. See 14 Del.C. §122(b)(26) and 14 DE Admin Code 614.1.0. The “minimum requirements” reference is an invitation to public schools to adopt non-uniform standards resulting in the hodgepodge of standards the Legislature sought to eliminate.

Second, proposed §4.1.7 should be deleted since it refers to “the following penalties” which are being deleted. Standing alone, §4.1.7 is meaningless.

Third, in §4.2, it would be preferable to delete the reference to a release of liability. As a practical matter, students reliant on an insulin pump, asthmatic inhaler, or autoinjectable epinephrine will be covered by Section 504 and their access to such life-saving supports cannot be conditioned on a parental release of liability. Moreover, the DOE regulation is literally mandatory, i.e., public schools must incorporate the release requirement into local standards even if they disfavor it. It would simplify the regulation to eliminate the requirement altogether.

Fourth, §4.3 is based on S.B. No. 181. There is some “tension” between S.B. No. 181 and disability-related laws. S.B. No. 181 (and §4.3) categorically bars a school nurse, employee or contractor from serving as a designated caregiver for the purpose of administering prescribed medical marijuana oil. In contrast, schools are required to accommodate the needs of students with disabilities under the ADA, Section 504, and the IDEA. In the medication context, public schools have been required to administer insulin, epinephrine, and other drugs. See, e.g., Region IX OCR LOF to Conejo Valley (CA) Unified School District, 20 IDELR 1276 (October 27, 1993) [district violated Section 504 by declining to establish an appropriate emergency response system for insulin-dependent child and disallowing trained laypersons to administer injections]; and Region III OCR LOF to Berlin Brothersvalley (PA) School District, 14 IDELR 353: 124, 125 (December 23, 1988) [district violated Section 504 by requiring parent to sign waiver of liability as precondition of administration of allergy medication]. Cf. Cedar Rapids School District v. Garrett, 526 U.S. 66 (1999) [adopting broad view of school responsibility to provide school health services to students with disabilities]. Administration of medications is a type of school health service. See 34 C.F.R. 300.34. Thus, if an IEP team determined that administration of prescribed marijuana oil were necessary to permit a student to attend school and receive a FAPE, the school would be responsible for implementing/facilitating that determination. At a minimum, the DOE may wish to include a non-regulatory note:
For students with disabilities, limitations on administration of medications are subject to exceptions based on the Americans with Disabilities Act, Section 504, and the IDEA, including a duty to provide school health services and health-related accommodations.

The Councils may wish to share the above observations with the Department and SBE with a courtesy copy to the Attorney General.

8. DOE Proposed Immunization Regulation [20 DE Reg. 227 (10/1/16)]

The Department of Education proposes to adopt some discrete revisions to it immunization standards to align with statutory law [14 Del. C. §131].

I reviewed the statute and proposed standards and identified only one (1) concern. The regulation applies to “public schools”, inclusive of districts and charter schools. See 14 Del. C. §131(a) and proposed §§1.0 and 5.4. In contrast, §6.0 refers to “superintendent or his or her designee” which would omit a charter school’s chief administrative officer. The DOE could consider the following amendment:

Evidence that the vaccines were administered shall be presented to the [district] superintendent [or charter school chief administrative officer or their respective designees] or his or her designee.

Alternatively, the DOE could simply refer to the “chief school officer”. See, e.g., 14 DE Admin Code 603.1.2. However, this might lead to confusion if interpreted to mean a school district principal. DOE regulations are inconsistent in references to charter school chief administrative officers. Compare, e.g., 14 DE Admin Code 601.5.1 (“head administrator”) and 14 DE Admin Code 103.12.2 (“lead authority”).

The Councils may wish to share the above observations and recommendation with the DOE and SBE.

9. DMMA Prop. Targeted Case Management Reg. [20 DE Reg. 247 (10/1/16)]

The Division of Medicaid and Medical Assistance (DMMA) proposes to adopt a Medicaid State Plan amendment affecting DDDS clients. In a nutshell, “targeted case management” (TCM) would be added as a State Medicaid Plan service with 2 target groups: 1) DDDS clients who are receiving residential services through the DDDS Medicaid waiver; and 2) DDDS clients who are receiving DDDS services and living in their own homes or with their families. At 248. The State plans to later file an amendment to the DDDS waiver effective January 1, 2017 to allow the second group to enroll in the waiver. The expanded waiver will be called “the Lifespan Waiver”. At 248. DDDS will “phase out” the existing “Family Support Specialists” (FSS) who currently provide some case management services to the second group. At 249. Instead, DDDS will issue an RFP to obtain some contract agencies who would hire targeted case managers (“Community Navigators”) to serve the second group under the waiver. See Supplement 3 to Attachment 3.1-A, p. 1. This approach should result in no additional cost. At 249. DDDS clients in the first group (residential clients) would continue to receive case management services from DDDS employees who would be designated “Qualified Support Coordinators”.

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I have the following observations.

First, the minimum credentials of both the “Community Navigators” (serving non-residential clients) and Qualified Support Coordinators” (serving residential clients) are weak. Apart from some DDDS training, the standard is as follows:

1. Have an associates degree or higher in behavioral, social sciences or a related field OR experience in health or human services support, which includes interviewing individuals and assessing personal, health, employment, social, or financial needs in accordance with program requirements.

Supplement 3 to Attachment 3.1-A, Page 6; Supplement 4 to Attachment 3.1-A, Page 6

These individuals are responsible for a host of high-level activities requiring expertise and skills, including monitoring health and welfare; ensuring implementation of service plans; responding and assessing emergency situations; participating in investigations of reportable incidents; assistance with linkages to obtaining services available through Medicaid, Medicare, private insurance, and other community resources; and coordination with MCO representatives, DVR, and educational coordinators. See Supplement 3 to Attachment 3.1-A, Pages 3-6. See also 42 C.F.R. 440.169. It is patent that more robust credentials will be necessary to perform the above functions in a meaningful way. These individuals must be expert in identifying and facilitating access to support services in complex federal, state, and private systems. Under the proposed standard, someone without even a high school diploma and minimal experience in human services will qualify to be hired as a case manager. Contrast the DMMA standards for a Medicaid MCO case manager:

1) nurse with 2 years of qualifying experience;
2) individual with 4 year degree in human services field plus 1 year experience; or
3) high school diploma plus 3 years of qualifying experience.

2016 DHSS MCO Contract, §3.7.1.2 [attached]

Second, the level of involvement with the DDDS clients is minimal. A unit of service is “1 month” so compensation is paid based on fulfilling the following de minimis activity once per month: “one (1) service contact that can include face-to-face or telephone contacts with the recipient or on behalf of the recipient”. See Attachment 4.19-B, Page 27; Attachment 4.19-B, Page 28. Thus, a case manager meets minimum standards for monthly compensation under the Medicaid program for making a single phone call per month. The combination of case managers with minimal credentials and minimal client contact is inconsistent with the recital that “every jurisdiction in the State will be able to receive high-quality, comprehensive case management services”. See Supplement 3 to Attachment 3.1-A, Page 6.

Third, there is no “caseload” benchmark in the Medicaid State Plan Amendment. It would be preferable to include a benchmark such as an upper cap on casemanager caseload. Contrast DMMA MCO case management “caseload management” standards, §3.7.1.5.3 of the 2016 DHSS-MCO contract [attached].
Fourth, it would be preferable to have case management provided by State employees rather contracting with private firms with a profit incentive. There may be minimal or no financial benefit to paying a broker agency which charges overhead and then pays case managers undefined compensation. The fee schedules for government and private providers for case management are the same. See Attachment 4.19-B, Page 27. For example, in practice, MCO case managers have proven much less responsive to client needs than State case managers. Their primary “loyalty” is to their employer, not the State. If CMS prefers a “firewall” between case management and direct service provision, the case managers could be placed under the Office of the Secretary. This was the approach adopted to separate the Long-term Care Ombudsman from DSAAPD since DSAAPD provides direct services in public nursing homes (e.g. DHCI; GBHC).

Fifth, DMMA should consider amending the following reference: “(i)nforms and assists an individual or his or her family to obtain guardianship or other surrogate decision making capability”. See Supplement 4 to Attachment 3.1-A, Page 4. Federal HHS is actively promoting alternatives to guardianship such as supported decision-making. See attachments. Delaware supported decision-making legislation (S.B. No. 230), co-authored by DHSS, was signed by the Governor on September 15, 2016. Consider the following substitute for the above reference: “(i)nforms and assists an individual or his or her family with surrogate decision making and assistance options, including supported decision-making agreements, powers of attorney, and guardianship.”

Sixth, DMMA should reconsider the following reference: “(f)acilitates referral to a nursing facility when appropriate.” See Supplement 4 to Attachment 3.1-A, Page 4. Placement of DDSS clients in nursing homes is highly disfavored. For that reason, DMMA implements the federal PASRR process. Cf. 16 DE Admin Code 5304.1. Moreover, DHSS has been actively prioritizing diversion of individuals from nursing homes through programs such as MFP and the DSHP+. Therefore, it is somewhat “odd” to specifically highlight and prioritize facilitation of referrals to nursing homes in the Medicaid State Plan Amendment.

The Councils may wish to share the above observations with DMMA, DDSS, and the Secretary’s Office.

10. **DFS Proposed Child Placing Agencies Regulation [20 DE Reg. 271 (10/1/16)]**

The Division of Family Services proposes a complete overhaul of its standards covering child placing agencies. Input on pre-publication drafts was obtained through public meetings in July, 2016 followed by review by a task force. The published regulation is comprised of 63 pages of deleted and proposed standards.

I have the following observations.

1. Section 4.0, definition of “administrative hearing”: The reference to “decision to place the facility on an enforcement action” is odd and counterintuitive. For example, a hearing is available to contest denial of a license application which is not conceptually “an enforcement action”. See §10.1. DFS may wish to consider adopting a more apt term (e.g. adverse OCCL decision” or “adverse OCCL action”) and substituting a conforming definition for the counterintuitive definition of “enforcement action”.
2. Section 7.2.6: I recommend deletion of the reference to “society’s best interests”. The concept is amorphous and one could posit that “society” is better off letting “high need” children with complex disabilities or short expected life spans expire.

3. Section 12.1: Consider substituting “state” for “State” since out-of-state adoption officials should have the same status as “international officials”. The capital version of “state” could be interpreted to only apply to Delaware.

4. Section 13.0: DFS may wish to align the content of this section with analogous or overlapping sections, including §§26.11 and 46.0. For example, §13.0 requires notice to OCCL if a child is “absent without permission, runs away” or “is abducted”. In contrast, §46.4.3 requires a foster parent to alert a licensee to “unknown location of the child” for any reason and §46.4.4 requires such notice for even “an attempt to remove the child from the foster home”, not simply an actual “abduction”. Note also that the foster parent must notify the licensee of “involvement of the child with law enforcement authorities” (§46.4.5) but the licensee is not required to notify DFS (§13.0). Likewise, note that §26.11 has a different injury threshold for notice to DFS - “serious bodily injury” versus any injury correlated with “medical/dental treatment” (§13.3). It would be preferable to have a single, identical standard. Finally, time periods for reporting are also inconsistent. For example, §26.11 requires “immediate” reporting of injuries while §13.3 allows such reporting within 1 business day.

5. Section 16.1.5 requires that “permanent records” be kept “indefinitely”. There is no definition of “permanent record” which could result in a lack of retention of records DFS would characterize as “permanent”. The term “indefinitely” suggests that records must be maintained forever. This may be an unrealistic standard.

6. Section 19.1 is “overbroad”. Literally, a licensee could not hire an accountant or bookkeeper who works off-site and has no contact with children if such an employee ever had a child removed from his/her custody for even dependency. There is no time limitation, i.e., the removal could have occurred 50 years ago. Moreover, removals based on “dependency” do not implicate “fault”, e.g., the caregiver may simply have lost a job or become so ill that care could not be provided. See, e.g., Title 10 Del.C. §901(8). The second sentence in §19.1 is “cryptic”. If DFS intends to authorize an exception to the first sentence, it should be made clear.

7. Section 19.4 is “overbroad”. It requires a licensee to “ensure a staff member provides documentation from a health care provider for the follow-up of known health conditions.” There is no definition of “known health condition”. That documentation is then shared with DFS. Employers cannot require an employee to disclose all “health conditions”. See attached EEOC guidance.

8. Section 19.6.1 could be improved by clarifying that the statute has time limitations on most offenses. Mere conviction of a “prohibited offense” is insufficient to disqualify a person from serving as an employee or volunteer in a child care context. Consider the following amendment:

9. Section 19.6 would effectively require an employer to immediately terminate the employment of an employee whose child has been currently removed under even an ex-parte order with marginal due process. The respondent may not be accorded a hearing for weeks (10 Del.C. §1043) but will have been fired. Moreover, the termination would apply to off-site employees (e.g. accountants; bookkeepers) who have no contact with children. This is overbroad.

10. Section 20.1.6 requires all licensee staff to “be physically and emotionally able to work with a child”. This is overbroad and discriminatory, especially when applied to staff who are not caring for children, e.g. janitor, receptionist, accountant, development director, or bookkeeper. Moreover, it is a violation of federal and State law to not provide reasonable accommodations to an employee with a disability, including reassignment of some duties to other employees. See 19 Del.C. §§722 and 724(a)(5). Finally, DFS adoption of such overbroad standards is inconsistent with 19 Del.C. §§741 and 744.

11. Section 20.1.11 contains the following ban: “possession of a controlled substance is prohibited while working”. Thus, an individual with ADHD could not have prescribed Ritalin or Adderall on his person. An individual with depression could not have a remedial medication on his person. In many cases this would amount to discrimination based on disability. Indeed, literally, a licensee could not employ a nurse to administer medications that would qualify as a controlled substance.

12. Section 26.13 literally states that a child is allowed to have any “restriction” that is typical for a child of the same age. It is “odd” to say someone has a right to a restriction.

13. Section 26.15 requires a licensee to have a policy to ensure that a foster parent does not subject a child to “exploitation”. Since “exploitation” is a form of “child abuse” as defined in §4.0, it may be preferable to amend §26.15 to more broadly cover child abuse and neglect.

14. Section 26.17.4 authorizes imposition of “physical, chemical, or mechanical restraint” with child placing agency approval. This is extremely problematic. Compare proposed Family Child Care Home regulation, §41.6.7 (categorically disallowing mechanical restraints or “restraining a child by a means other than holding”). There is a statutory ban on use of chemical and mechanical restraints in schools. See 14 Del.C. §4112F(b) which reflects a State public policy of disallowing their use. DHSS bans use of chemical restraint in facilities such as Advoserv. See 16 DE Admin Code 3320.20.11.11. DFS will not even be aware that mechanical and chemical restraints have been approved by a child placing agency or the frequency of use.

15. Section 29.2.2 should be expanded to include an IFSP. Compare §30.1.11.5. It could also be expanded to include a Section 504 plan.

16. Section 34.1 only contemplates enrollment of “school-age” children in an educational program. That term is defined in §5.0 to only include children of kindergarten age upwards. This ignores children with disabilities entitled to special education at birth or age 3. See 14 Del.C. §§3101(1) and 1703(l)(m). It also ignores infants and toddlers eligible for IDEA-C services pursuant to 16 Del.C. §§210-218.

18. Section 40.1.6 could be amended to include “power strips”. Compare proposed Child Care Home regulation, §21.10.

19. Section 40.1.13 should be amended to include “vaping” or “smoking (as defined in 16 Del.C. §2901)”. See 16 Del.C. §2903.

20. Sections 40.1.24 (foster care) and 51.3.25 (adoptive home) include a few pet references. However, while household member profiles/background checks are addressed in detail, there is no standard addressing dangerous animals (e.g. snakes; alligators; pit bulls). An applicant may not even have to affirmatively disclose the presence of such animals. A child could also be allergic to certain animals. A regulation addressing poisonous or aggressive animals is being deleted. See proposed superseded §111.2. A variation of the superseded standard should be retained.

21. In §50.5, the reference to “under Delaware Code” is vague. DFS may wish to adopt more specific references.

The Councils may wish to share the above comments with DFS with a courtesy copy to the Employment First Commission.

11. DFS Prop. Family & Lg. Family Child Care Home Reg. [20 DE Reg. 270 (10/1/16)]

The Division of Family Services proposes a complete overhaul of its standards covering family child care homes and large family child care homes. Input on pre-publication drafts was obtained through public meetings in July 2016 followed by review by a task force. The Division is repealing separate standards for family homes and large family homes in favor of a single set of standards covering both.

I have the following observations.

1. Section 3.1 includes preschool children living in the home in the calculation of the upper capacity limit. However, this section indicates that grandchildren, nieces, nephews, and stepchildren are not counted in calculating the limit. This makes no sense. A grandparent licensee could have several co-habiting preschool grandchildren or a parent licensee could have several co-habiting preschool stepchildren. They should count towards a capacity limit on the same basis as a biological child. Relative caregivers are common. See 14 Del.C. §202.
2. Section 12.5 is “overbroad”. Literally, a licensee could not hire an accountant or bookkeeper who works off-site and has no contact with children if such an employee ever had a child removed from his/her custody for even dependency. There is no time limitation, i.e., the removal could have occurred 50 years ago. Moreover, removals based on “dependency” do not implicate “fault”, e.g., the caregiver may simply have lost a job or become so ill that care could not be provided. See, e.g., Title 10 Del.C. §901(8). The second sentence in §12.5 is “cryptic”. If DFS intends to authorize an exception to the first sentence, it should be made clear.

3. Section 12.11 ostensibly requires the licensee to require all employees, even those working off site with no contact with children, to execute a blanket release of all medical and mental health records. This is overbroad and creates a conflict with federal laws exposing the licensee employer to liability. See attached summary of EEOC decision. Reliance on a state regulation is not a defense:

The ADA does not override State or local laws designed to protect public health and safety, except where such laws conflict with the ADA requirements. If there is a State or local law that would exclude an individual with a disability from a particular job or profession because of a health or safety risk, the employer still must assess whether a particular individual would pose a "direct threat" to health or safety under the ADA standard. If such a "direct threat" exists, the employer must consider whether it could be eliminated or reduced below the level of a "direct threat" by reasonable accommodation. An employer cannot rely on a State or local law that conflicts with ADA requirements as a defense to a charge of discrimination.


4. Section 12.13 may violate the ADA: “A licensee shall ensure a staff member diagnosed or treated for mental illness that might create a significant risk of harm to children is not hired.” The employer cannot simply decide to not hire an individual with a disability based on a perception that the applicant “might create a significant risk of harm”. The employer would have to determine if the risk could be eliminated or reduced by reasonable accommodation. See above quotation. Moreover, the applicable standard is “direct threat to health or safety”, not “risk of harm”. Parenthetically, adoption of regulatory and policy standards based on stereotypical, pejorative views of mental illness are contrary to State public policy. See 19 Del.C. §§741 and 744.

5. Section 12.17 is unduly restrictive and ill-conceived:

12.17. A licensee shall not provide care for a person recovering from a long-term illness or surgery requiring nursing care at home during the hours children are in care.
The categorical ban would apply even if the family child care home had 2 staff members “caring” for a single 14 year old child. The categorical ban would apply even if a private duty nurse were present to provide the nursing care. From a public policy perspective, the ban will create hardships for families with recovering family members who would like to recuperate at home. The ban will prompt the “recovering person” to unnecessarily enter institutional, nursing facility care. Finally, the ban is inconsistent with federal public policy discouraging discrimination against persons based on their “association” with someone with a disability. See 42 U.S.C. 12112(b)(4).

5. Section 15.0 omits notification to OCCL if a child is “missing” or there is an attempted or actual abduction. Compare proposed Child Placement Agency regulation, §§13.0 and 46.4.3.

6. Section 15.3.5 requires a licensee to notify OCCL if any household member or staff member “develops a serious health condition or is diagnosed with a mental illness” and submit documentation/medical clearance to the OCCL. The requirement would apply to even employees who are off-site and have no contact with children. It is indicative of a pervasive, hysterical and pejorative view of mental illness and health conditions throughout the regulation. This standard presumes that anyone with a serious health condition or any mental health diagnosis poses a significant risk to children unless “cleared” by medical personnel. Employers are barred from asking employees about mental illness unless the employer has a reasonable belief, based on objective evidence, that the employee poses a direct threat. It is impermissible to adopt a legal presumption that everyone with a mental health diagnosis is dangerous until medically cleared.

7. Section 18.3 authorizes exemption from immunization based on religion. DFS may wish to review 14 Del.C. §131 and 20 DE Reg. 227 (10/1/16) and/or consult DPH to determine if more prescriptive standards should apply than a simple recital “documentation is required”. For example, the statutory form of affidavit for students disallows an exemption if based on “political, sociological or philosophical view of a merely personal code”. Section 18.3 does not require an affidavit and suggests that the objection could be relatively informal.

8. Section 21.18 requires only a single toilet irrespective of the size of the household and number of children in care. This should be reconsidered. For example, if a household member is taking a shower in the bathroom, children may have no access to a toilet. Compare 16 DE Admin Code 3230.5.9 (1 toilet per 4 residents).

9. Section 21.24 should be amended to include “vaping” or “smoking (as defined in 16 Del.C. §2901)”. See 16 Del.C. §2903.

10. Sections 241.0 and 25.0, disallowing trampolines and requiring children to wear helmets when riding bikes merit a strong endorsement since correlated with TBI prevention.
11. In Section 32.3, DFS may wish to further define “notify OCCL”. For example, the analogous proposed Child Placement Agencies regulation includes a definition of “direct voice contact” (§4.0) and otherwise refers to “call OCCL and speak to someone” (§13.0) as juxtaposed to leaving a message.

12. Historically, DHSS reported that some child care providers refused to cooperate with IDEA-C service providers (e.g. speech therapists; occupational therapists) by disallowing or discouraging on-site services. See 16 Del.C. §§210-218. Under federal law, IDEA-C services are to be provided in “natural environments”, including day care settings. See attachments. It would be preferable to include a requirement of licensee cooperation with IDEA-C service providers in §39.0.

13. Section 41.6.7 contains appropriate restrictions on use of some forms of restraint. It could be embellished by a general ban on “mechanical restraint”. By analogy, there is a statutory ban on use of mechanical restraints in schools. See 14 Del.C. §4112F(b) which reflects a State public policy of disallowing their use.

14. Section 41.6 could be improved by disallowing chemical restraint. There is a statutory ban on use of chemical restraints in schools. See 14 Del.C. §4112F(b). DHSS bans use of chemical restraint in facilities such as AdvoServ. See 16 DE Admin Code 3320.20.11.11.

15. Section 41.0 could be improved by disallowing “seclusion”. Seclusion is distinct from “time-out” and a licensee could argue that there are no limits on seclusion, including locking a child in a room. Compare 14 Del.C. §4112F(a)(5)(6). There is a statutory ban on seclusion in schools. See 14 Del.C. §4112F(b). DHSS bans use of seclusion in facilities such as AdvoServ. See 16 DE Admin Code 3320.20.11.13 and 14. Moreover, definitions of “time-out” and “seclusion” should be added to §4.0.

16. Section 58.1.11 includes the following ban: “possession of a controlled substance is prohibited while working”. Thus, an individual with ADHD could not have prescribed Ritalin or Adderal on his person. An individual with depression could not have a remedial medication on his person. In many cases this would amount to discrimination based on disability. Indeed, literally, a licensee could not employ a nurse to administer medications that would qualify as a controlled substance.

The Councils may wish to share the above observations with DFS with a courtesy copy to the Employment First Commission and, given Comment #12, the Interagency Coordinating Council.

15
12. **DFS Proposed Large Family Child Care Homes Reg. [20 DE Reg. 271 (10/1/16)]**

The Division of Family Services (DFS) proposes to repeal its “Large Family Child Care Homes” regulation in its entirety. Revised standards are being incorporated into the “Family Care Homes” regulation (reviewed above) resulting in a single set of regulations.

The Councils may wish to endorse this approach since it is easier to administer a single set of standards and the two sets of regulations overlapped considerably. See 20 DE Reg. 270 and 327 (10/1/16).

Attachments

E:legis/2016/1016bills
F:pub/bjh/legis/2016p&l/1016bills
DATE: August 16, 2016

TO: Daniese McMullin-Powell
    Chairperson
    State Council for Persons with Disabilities
    410 Federal Street, Suite 1
    Dover, DE 19901

FROM: Glyne Williams, DMMA
      Planning, Policy and Quality Unit

RE: 19 DE Reg. 982 [DMMA Proposed ABLE Account Regulation (5/1/16)]

Thank you for your recent memorandum regarding the Division of Medicaid and Medical Assistance (DMMA) notice soliciting comments on its proposal to adopt regulations implementing the Achieving a Better Life Experience Act of 2014 ("ABLE" Act). The proposed regulation was published as 19 DE Reg. 982 in the May 1, 2016 issue of the Register of Regulations. DMMA has considered your comments and responds as follows.

You write,

The Act authorizes the establishment of a special account for the benefit of a qualifying individual with a disability. Funds in such an account, which will not be a countable resource and distributions from such a fund for a qualified disability expense (QDE), are not countable income for public benefits programs. Implementing State legislation was adopted in 2015 and is codified at 16 Del.C. §§9601A-9608A. New State legislation (H.B. 358) was introduced on May 4, 2016.

SCPD has the following observations on the proposed regulation.

First, in §20330.2.1.1, the definition of “person with signature authority” merits reconsideration. The first sentence reads as follows:

“Person with signature authority” means a person who can establish and control an ABLE account for a designated beneficiary who is a minor child or is otherwise incapable of managing an account.

The federal regulations do not require an adult to “be incapable of managing an account” to designate a “person with signature authority.” See, e.g., the attached proposed regulation published at 80 Fed Reg. 35611 (June 22, 2015):

If the designated beneficiary is not able to exercise signature authority over his or her ABLE account or chooses to establish an ABLE account but not exercise signature authority, references to the designated beneficiary with respect to his or her actions include actions by the designated beneficiary’s agent under a power of attorney or, if none, a parent or legal guardian of the designated beneficiary.

[emphasis supplied] A “competent” adult can simply choose to not exercise signature authority.

Agency Response: DMMA appreciates the Council’s perspective on the wording of this particular definition, which was taken from Supplemental Security Income (SSI) policy (see SI 01130.740 Achieving a Better Life Experience (ABLE) Accounts), on which Medicaid Long-Term Care (LTC) eligibility policy is based. We have modified this definition for the final regulation, substituting the phrasing above for the original version.
“Person with signature authority” means a person who can establish and control an ABLE account for a designated beneficiary. If the designated beneficiary is not able to exercise signature authority over his or her ABLE account, or chooses to establish an ABLE account but not exercise signature authority, references to the designated beneficiary with respect to his or her actions include actions by the designated beneficiary’s agent under a power of attorney or, if none, a parent or legal guardian of the designated beneficiary.

Second, in §20330.2.1.1, the definition of “ABLE program” refers to a program established or maintained “by a State (or agency or instrumentality thereof)...” This is consistent with the proposed federal regulation. See 80 Fed Reg. at 35612(June 22, 2015). However, SCPD understands that many states are contemplating implementation through a consortium of states. Therefore, DMMA could consider expanding the reference as follows: “by a State or consortium of states (or agency or instrumentality thereof)...”

Agency Response: DMMA agrees with the suggested revision of this section of the proposed policy. We have revised the definition for the final regulation as follows:

“ABLE Program” means a program established and maintained by a State or consortium of states (or agency or instrumentality thereof) through which interested individuals can open ABLE accounts.

Third, for similar reasons, DMMA could consider amending the definition of “eligible individual” as follows: “a resident of this State, a contracting state, or a state participating in a consortium arrangement who is: ...”

Agency Response: DMMA agrees with the suggested broaden the language used in this definition. We have revised the definition for the final regulation as follows:

“Eligible Individual” means a resident of this State, or any state, in which an ABLE program is established who is:

- Entitled to benefits based on disability or blindness under Title II or XVI of the Social Security Act and such blindness or disability began before the age of twenty-six (26); or
- An individual with respect to whom a disability certification, meeting the requirements of the Stephen Beck, Jr., ABLE Act of 2014, is filed.

Fourth, for similar reasons, DMMA could consider amending §20330.2.1.2.2 as follows: “The State or consortium ABLE program that is administering the account.”

Agency Response: DMMA agrees with the suggested revision of this section of the proposed policy. We have revised this section for the final regulation as follows:

20330.2.1.2.2 The State or consortium ABLE program that is administering the account;

Fifth, in §20330.2.1.1, the definition of “eligible individual” requires the person to be a resident of Delaware or “a contracting state”. The proposed federal regulation would allow some persons (e.g. military) to keep an account even if the person is no longer a resident of the state. See attached 80 Fed Reg at 35608. Therefore, there is some “tension” between the “residency” requirement and the proposed federal regulation. Moreover, consistent with the attached January 11, 2016 article, Congress amended the law so an eligible person can open an account in any state, regardless of where the person resides.

Agency Response: DMMA appreciates the Council’s comment on this subject. However, we believe that the revised definition of “Eligible Individual” (see response to item three (3) above) is sufficiently broad to cover individuals who may be beneficiary of an ABLE Account, regardless of their state of residence.

Sixth, in §20330.2.1.3, second sentence, there is a plural pronoun (“their”) with a singular antecedent (“person”). This can be easily corrected by substituting “the person’s” for “their”.
Agency Response: DMMA agrees with the Council’s suggested revision. The final regulation will be revised as follows:

20330.2.1.3 ABLE Account Contributions

Contributions made to an ABLE account by persons other than the designated beneficiary shall not be excluded from the countable income of the person who makes the contribution. The fact that a person uses the person’s own income to contribute to an ABLE account does not mean that income is not countable for Medicaid purposes.

Seventh, in §20330.2.1.5, correct the grammar by substituting “the beneficiary’s” for “their”.

Agency Response: DMMA agrees with the Council’s suggested revision. The final regulation will be revised as follows:

20330.2.1.5 ABLE Account Balance

Exclude the balance of a designated beneficiary’s ABLE account from the beneficiary’s countable resource computation when determining the designated beneficiary’s eligibility.

Eighth, §§20330.2.1.6.1 and 20330.2.1.6.2 treat distributions for housing less favorably than other distributions. If a housing distribution is made on May 31 and paid to a landlord on June 1, the entire housing distribution would be considered a countable resource for the month of June. This is an unreasonable approach.

Agency Response: DMMA appreciates the Council’s feedback on this issue. However, LTC Medicaid eligibility policy is based on SSI policy. SSI policy treats distributions for housing expenses differently than other Qualified Disability Expenses (QDE). 26 USC §529A Treatment of ABLE Accounts Under Certain Federal Programs (a)(1) states the following:

“(a) Account Funds Disregarded for Purposes of Certain Other Means-Tested Federal Programs.—Notwithstanding any other provision of Federal law that requires consideration of 1 or more financial circumstances of an individual, for the purpose of determining eligibility to receive, or the amount of, any assistance or benefit authorized by such provision to be provided to or for the benefit of such individual, any amount (including earnings thereon) in the ABLE account (within the meaning of section 529A of the Internal Revenue Code of 1986) of such individual, any contributions to the ABLE account of the individual, and any distribution for qualified disability expenses (as defined in subsection (e)(5) of such section) shall be disregarded for such purpose with respect to any period during which such individual maintains, makes contributions to, or receives distributions from such ABLE account, except that, in the case of the supplemental security income program under title XVI of the Social Security Act [42 U.S.C. 1381 et seq.],”

Therefore, DMMA’s LTC eligibility policy addresses QDEs relating to housing expenses in accordance with SI 01130.740(D)(2).

Thank you again for your review and feedback related to the proposed additions to Medicaid LTC eligibility policy addressing ABLE accounts. DMMA is pleased to provide the opportunity to receive public comments and greatly appreciates the thoughtful input given.

Cc: Stephen M. Groff, Director, DMMA
DATE: August 19, 2016

TO: Ms. Jamie Wolfe, Chairperson
State Council for Persons with Disabilities
410 Federal Street, Suite 1
Dover, DE 19901

FROM: Glyne Williams, DMMA
Planning, Policy and Quality Unit

RE: 20 DE Reg. 11 [DMMA Proposed Medicaid Autism Services Disorder Regulation (7/1/16)]

Thank you for your recent memorandum regarding the Division of Medicaid and Medical Assistance (DMMA) notice soliciting comments on its proposal to amend the Medicaid State Plan to address coverage and reimbursement of treatment services for beneficiaries up to age 21 with a diagnosis of autism spectrum disorder (ASD). The proposed regulation was published as 20 DE Reg. 11 in the July 1, 2016 issue of the Register of Regulations. DMMA has considered your comments and responds as follows.

State Council for Persons with Disabilities (SCPD) thanks DMMA for making changes to the proposed regulation based on its earlier comments. SCPD offered additional comments on the revised regulation which are summarized below.

Your comments are as follows:

(A) SCPD questions the change in wording from “services to treat Autism Spectrum Disorder” to “behavioral interventions” because you believe that the revised wording is more limiting in scope. SCPD also indicates that ASD treatment is not limited to modification of behavior.

Agency Response: It was not DMMA’s intention to limit the scope of ASD services by using the words “behavioral interventions,” but we can understand why this language may appear to be more limiting. Accordingly, DMMA has changed the reference to “interventions” to “services” or “assessments and services” where appropriate. Council is correct that ASD treatment is not limited to modification of behavior. However, it was the intent of this SPA to establish and clarify coverage of behavioral services for Medicaid recipients up to twenty-one (21) years of age who have a diagnosis of ASD. These services addressing behaviors have not heretofore been well articulated in the State Plan, and have been added to augment, not replace, other services already covered under the State Plan. The practitioner types enumerated in the proposed regulation are consistent with the delivery of behavioral health services. However, non-behavioral ASD treatment services, such as therapies, physician services, and other licensed practitioner services are already, and continue to be, covered under other sections of the Medicaid State Plan.
(B) SCPD objected to language in the Plan that the council believes confers unilateral control over caregiver participation in the implementation of a treatment plan to a "practitioner". SCPD proposed alternative language that indicates a more collaborative approach to determining the level of caregiver participation.

Agency Response: DMMA acknowledges this comment and has adopted the alternative language proposed. Page 6 Addendum 1e of Attachment 3.1-A, (c) ASD Treatment Services, (12) now reads:

"Include recommendations for training, support, and participation of the parent/guardian, and other persons chosen by the child as appropriate, to benefit the Medicaid eligible child, as described in the treatment plan. The expected level of participation of all caregivers shall be included in the Behavior Support Plan or ABA Treatment Plan. This participation also acts as training of the caregiver for the benefit of the child and enables the caregiver to be able to reinforce the services for the child in a clinically effective manner."

(C) SCPD pointed out a grammatical error on page 20 of the proposed regulation.

Agency Response: DMMA has made this correction.

DMMA is appreciative of the qualified endorsement by SCPD. DMMA is pleased to provide the opportunity to receive public comments and greatly appreciates the thoughtful input given. DMMA will publish this regulation as final in the October 1, 2016 Delaware Register.

Cc: Stephen M. Groff, Director, DMMA
June 27, 2016

Tina Shockley
Education Associate – Policy Advisor
Department of Education
401 Federal Street, Suite 2
Dover, DE 19901

RE: 19 DE Reg. 1057/14 DE Admin. Code 616 [DOE Proposed Uniform Due Process Procedures for Alternative Placement Meetings and Expulsion Hearings Regulation (June 1, 2016)]

Dear Ms. Shockley:

The Governor’s Advisory Council for Exceptional Citizens (GACEC) has reviewed the Department of Education (DOE) proposal to create a new regulation defining uniform due process standards for disciplinary matters and placement in alternative disciplinary settings. The regulation was originally proposed in December 2015 but has been republished to incorporate changes made based on comments provided by Attorney General Matt Denn, the ACLU Foundation of Delaware, Representative Kimberly Williams, the Governor’s Advisory Council for Exceptional Citizens, the State Council for Persons with Disabilities and various school district personnel. The letter submitted in December is attached for your reference. Council would like to share the following observations on the current proposal and reiterate some of our concerns from the earlier proposal.

1. In §2.0, the definition of “Alternative Placement Team” contains the following recital: “Other individuals may be invited as determined by the APT.” This is unclear. Does this mean that any single member of the team is able to invite a participant or would the entire team have to agree to invite a participant? The latter interpretation would be highly objectionable since it would mean that the Division of Services for Children, Youth and their Families (DSCY&F) could be barred from having more than one participant and that a parent would not be able to invite a participant (e.g. school psychologist; Wellness Center therapist).

2. In §2.0, definition of “Alternative Placement Team”, the student is not a member of the team. The student should be a member in order to provide input. Individuals are more likely to accept a decision if they have had a voice in the decision-making. By law, alternative school programs are required to reflect “research best-practice models”. See

HTTP://GACEC.DELAWARE.GOV
3. In § 2.0, definition of “parent” includes “a student who has reached the age of majority”. While this corrects some problems where an adult student might not receive information that only goes to a parent, it creates odd language anywhere there is a reference to both the student and the parent. Moreover, it creates an ambiguity where something is to be communicated only to the “parent.” The way the definition is written, notice to a “parent” of an adult student could arguably be accomplished by contacting the adult student’s parent and not the adult student. This is unacceptable. The language may be corrected throughout the regulation by changing the definition of parent to “‘Parent’ is defined as the student, if the student has reached the age of majority. If the student has not reached the age of majority, ‘parent’ is defined as [biological parent, adopted parent, etc.]”

4. In §2.0, definition of “Building Level Conference”, the contemplated meeting “is held by phone or in person”. The regulation is silent on who decides whether the meeting is held by phone or in person. The regulation should be amended to clarify that the choice should be that of the parent/student. There are two advantages to this approach: 1) an in-school meeting reinforces the importance of the conference; and 2) a phone call from a school representative could easily be misconstrued as an informal communication and not a “Building Level Conference” required by Goss v. Lopez. Since the definition of “principal” includes a “designee”, the parent could receive the call from a guidance counselor, educational diagnostician, or other support staff which could easily be misconstrued.

5. In §2.0, the definition of “Expulsion” contains an excess of substantive standards and ramifications of expulsion. Such substantive information does not belong in a definition. See Delaware Administrative Code Style Manual, §4.3.

6. In §2.0, the definition of “Grievance” envisions a complaint to a school administrator; however, there are no specific “due process” procedures for such grievances in the regulation. The regulation sets minimum procedures as “similar to the grievance guidelines as posted on the Department of Education website.” At present, there are no guidelines posted that can be easily located. As such, it is unclear whether this provides any significant due process protections.

7. In §2.0, definition of “Student Review”, the sole focus is on student progress with no mention of whether the student’s required “Individual Service Plan (ISP)” has been implemented. See 14 DE Admin Code 611.6.1. In fairness, the “Review” should include an assessment of the extent to which the services and supports included in the ISP were provided.

8. In §2.0, definitions of “Suspension (Long-term Suspension)” and “Suspension, Short-term (Short-term Suspension), the DOE establishes different due process standards for suspensions up to 11 consecutive school days versus 11 or more school days. While such benchmarks may be appropriate general standards, they completely ignore the
alternate significant deprivation/change of placement standard - a pattern of short-term removals of less than 11 days. Consider the following:

A. The IDEA regulation (34 C.F.R. 300.536) codifies case law and long-standing federal policy as follows:

... (A) change in placement occurs if -

(1) The removal is for more than 10 consecutive school days; or
(2) The child has been subjected to a series of removals that constitute a pattern -
   (i) Because the series of removals total more than 10 school days in a school year;
   (ii) Because the child's behavior is substantially similar to the child's behavior in previous incidents that resulted in the series of removals; and
   (iii) Because of such additional factors as the length of each removal, the total amount of time the child has been removed, and the proximity of the removals to one another.

B. The federal Department of Education Office for Civil Rights has adopted a similar approach for decades. See OCR Senior Staff Memo, IDELR, SA-52 ((October 28, 1988). For a consistent view, see Region VI LOF to Ponca City (OK) School District, 20 IDELR 816 (July 19, 1993); and Region IV OCR LOF to Cobb County (GA) School District, 20 IDELR 1171 [district cited for maintaining a disciplinary policy which did not address series of short suspensions amounting to a change in placement].

Apart from the "pattern" approach, the Delaware regulation could reinstate the approach adopted by the Department and promoted by the Attorney General's Office, that characterized a "suspension for more than 10 days, either consecutively or cumulatively, in any school year ...a change in placement". Thus, if a student has had a five day suspension and a district proposes to impose a second six-day suspension, it would trigger due process consistent with a single 11-day suspension. This approach has the advantage of simplicity in administration and facilitates earlier reviews and interventions.

9. In §2.0, the definitions of "Suspension (Long-term Suspension)" and "Suspension, Short-term (Short-term Suspension)" refer to "being removed from the Regular School Program". The definition of "Regular School Program" is limited to "participation in daily course of instruction and activities within the assigned classroom or course". The regulation ignores suspensions from bus transportation which should be treated the same as an exclusion from school. See Region IV OCR LOF to Tennessee State Dept. Of Education, IDELR 305:51 (April 24, 1989); OCR Policy Letter to C. Veir, 20 IDELR 864, 867 (December 1, 1993).

10. Under §3.1.1.3, a principal's preliminary investigation of offending student conduct requires the principal to make "reasonable efforts" to "include the allegedly offending
student” (emphasis added). Lack of interviewing a student to obtain the student’s version of events may manifestly undermine the validity and reliability of the investigation results. It may also lead to unjustified police referrals under §3.2.1. Thus, the language should be stronger. First, “include” should be changed to “interview.” To further strengthen the language, the regulation could read “the principal shall interview the allegedly offending student or state with specificity the reasons the student could not be interviewed.” This places an obligation on the principal but leaves an “out” in cases where it would not be possible to interview the student.

11. §§4.1 and 4.1.1 should be amended consistent with item 9 above. The definition of “Regular School Program” is limited to “participation in daily course of instruction and activities within the assigned classroom or course”. The regulation ignores suspensions from bus transportation which should be treated the same as an exclusion from school. See Region IV OCR LOF to Tennessee State Dept. Of Education, IDELR 305:51 (April 24, 1989); OCR Policy Letter to C. Veir, 20 IDELR 864, 867 (December 1, 1993).

12. §4.1.1.3 could be improved as follows:

The student shall be given an explanation of the evidence supporting the allegation(s), including statements of each witness, and an opportunity to present his/her side of the story including any evidence.

13. In §4.2.1, Council recommends deletion of the term “welfare” since it is obtuse and immediate removal should be justified based on a threat to health or safety. Cf. Title 14 Del.C. §4112F(b)(2).

14. §5.1.2 allows a Superintendent to extend a short-term (up to 10 days) suspension with no time limit. For example, if the student is being referred for action to the Board of Education and the Board will not meet for a month, a 10-day suspension becomes a 40-day suspension. On the 11th day, the student is offered “Appropriate Educational Services” which can be in another setting (e.g. homebound) with no additional due process. Switching a child to homebound, or a different setting with new instructors, will predictably prevent a child from maintaining academic progress. Providing educational services on the 11th day should also be reconsidered. A similar New Jersey regulation, §6A:16-7.2(a)(5)1, reinstates academic instruction within five days of suspension. This is a more progressive approach which allows a student to keep up with coursework.

15. In §5.4 the notice should include the protocol for appeal, including the timetable and method to appeal pursuant to §5.4.1. As it currently reads, the regulation only requires the provision of “information regarding the districts/charters appeal or grievance process.” Information about the grievance process and the appeals process should be included. Additionally, there should be more specificity as to the information provided. For example, the time allowed to file an appeal should be included.

16. In §5.5, the decision to convene a conference in-person or by phone should be the choice
of the student/parent. See discussion in item #4 above. Furthermore, the following sentence is unclear: “The Principal may waive the conference requirement.” This could be interpreted in two ways: 1) the principal can waive the conference upon parental request; or 2) the principal may unilaterally decide to not convene a conference even if a student or parent desires one. The former approach would be preferable.

17. §§7.2.1.3 and 7.2.1.4 should include a requirement that the notices include a description of due process and appeal rights.

18. §7.2.1.5.1 could be improved by explicitly authorizing the Committee to include parent/student participation.

19. §7.2.1.7 authorizes the Principal to convene a “Building Level Conference” to inform the parent/student of a referral to an Alternative Placement. The section explicitly applies to special education students. The Principal should not be making a unilateral referral to change the placement of a special education student. That is the responsibility of the IEP team.

20. §7.2.1.7.2 allows a conference to be held by phone or in person. Consistent with item #4 above, this section should be amended to clarify that the choice should be that of the parent/student.

21. §7.2.1.8 contemplates advance written notice but does not identify the time period (e.g. three business days).

22. §7.4.1.4 solely focuses on the responsibilities of the student to the exclusion of the responsibilities of the program, i.e., to fulfill services and supports identified in the required ISP. See 14 DE Admin Code 611.6.1. This is not balanced. Although the regulation refers to the ISP, it does not refer to the program’s obligations under the ISP.

23. §8.1.1 contemplates a “Student Review” which omits an assessment of the extent to which the program provided the services and supports required by the ISP. The Review is incomplete without the inclusion of such information. See discussion under item #7 above. The reference to “the student’s strengths and weaknesses in connection with their individualized goals and expectations” is not sufficient because it does not reference the extent to which the program provided the required services and supports.

24. §10.2.3.1 allows a conference to be held by phone or in person. Consistent with item #4 above, this section should be amended to clarify that the choice should be that of the parent/student.

25. §10.2.3 recites that the Principal will inform the parent/student that “the student will be serving a Short-term Suspension pending the outcome of the Expulsion hearing”. This is not accurate. In many cases, this process will exceed the duration of a “short-term” suspension. Moreover, this section should be amended to explicitly advise the
parent/student that “Appropriate Educational Services” will be provided during the pendency of proceedings. See discussion in item #14 above. See also Appeal of Student W.D. from Decision of the W. Board of Education, Decision & Order (Delaware State Bd. Of Education March 21, 1991), at 15-16 [districts cannot simply place students on indefinite suspension pending an expulsion hearing without alternative educational services].

26. In §10.3.4, the term “If requested” should be deleted. There is very little time to prepare for the hearing and processing a “request” may take days. The notice should automatically include the information. Compare Title 14 Del. C. §3138(a)(4) reflecting better practice.

27. §10.3.11.1 appears to limit representation to an attorney. Historically, non-attorneys were permitted to represent students in expulsion hearings. See, e.g., p. 14 of Guidelines on Student Responsibilities & Rights prepared by Attorney General’s Office and adopted by State Board of Education, Appeal of Student W.D. from Decision of the W. Board of Education, Decision & Order (Delaware State Bd. Of Education March 21, 1991), at 16 [authorizing representation by “an adult advisor”]. The Department may wish to clarify whether representation in expulsion hearings is limited to attorneys.

28. §10.3.11.4 recites that the student can obtain a transcript of the expulsion hearing “at the student’s expense”. In most cases, the student would request the transcript in connection with an appeal to the State Board of Education. Unless changed in recent years, State Board Rules have historically required the district to submit the transcript at the district’s expense. See 9 DE Reg. 1997, 2009, 2011 (June 1, 2006), Rules 3.4.1 and 4.6 [“The transcript shall be prepared at expense of the agency below.”] At a minimum, this should be disclosed to the student and parent rather than simply advising them that they can obtain a transcript at their expense.

29. §10.3.12 authorizes a waiver of the expulsion hearing accompanied by an admission of the charges which “does not absolve the student from required consequence”. It would be preferable to include another option, i.e., admission of the conduct but contested hearing on the penalty. There are conceptually two prongs to the expulsion decision-making: 1) do facts support violation of Code of Conduct; and 2) is penalty commensurate with offense. For example, the student could argue that an expulsion is too harsh or expulsion for 90 days is more appropriate than expulsion for 180 days. See, e.g., Guidelines on Student Responsibilities & Rights, p. 11 and Appendix, Par. 30, holding that “discipline shall be fair ... and appropriate to the infraction or offense” and authorizing “a detailed hearing on the penalty”.

30. In the entire ten page regulation, the only section addressing additional protections for students with disabilities is §11.0 which consists of four extremely unclear and unenlightening sentences:

11.0 Students with Disabilities
11.1 Nothing in this regulation shall alter a district/charter school’s duties under the
Individual (sic “Individuals”) with Disabilities Act (IDEA) or 14 DE Admin Code 922 through 929. Nothing in this regulation shall prevent a district/charter school from providing supportive instruction to children with disabilities in a manner consistent with the Individuals with Disabilities Education Act (IDEA) and Delaware Department of Education regulations.

11.2 Nothing in this regulation shall alter a district/charter school’s duties under Section 504 of the Rehabilitation Act of 1973 or the Americans with Disabilities Act to students who are qualified individuals with disabilities. Nothing in this regulation shall prevent a district/charter School (sic “school”) from providing supportive instruction to such students.

This is a reluctant and weak approach to protecting the rights of students with disabilities. Instead of adopting a leadership role in providing districts and charter schools with useful guidance, the negative parenthetical approach adopted in §11.0 offers negligible direction. According to the Parent Information Center, nearly 23% of Delaware students suspended or expelled are students with disabilities and, of those students, 68% are students of color. See July 27, 2014 News Journal article. Disproportionate discipline of students with disabilities and other protected classes merits positive action by the Department to promote district and charter school conformity with federal and State civil rights protections.

Thank you in advance for your consideration of our comments. Please contact me or Wendy Strauss at the GACEC office if you have any questions on our observations and recommendations.

Sincerely,

Robert D. Overmiller
Chairperson

RDO:kpc

CC: The Honorable Matthew Denn, Delaware Attorney General
Dr. Steven H. Godowsky, Secretary of Education
Dr. Teri Quinn Gray, State Board of Education
Mr. Chris Kenton, Professional Standards Board
Mary Ann Mieczkowski, Department of Education
Matthew Korobkin, Department of Education
Terry Hickey, Esq.
Valerie Dunkle, Esq.
Kathleen McRae, ACLU

Enclosure
A New Path: 2016 PCPID Report to the President Now Available

The President's Committee for People with Intellectual Disabilities (PCPID) 2016 Report is now available online.

The report, Strengthening an Inclusive Pathway for People with Intellectual Disabilities and their Families, recognizes the "great strides" made since President John F. Kennedy established a blue-ribbon panel to address the needs of people with intellectual disabilities and their families and PCPID Chairman Jack Brandt notes that, "Despite these advances, the trajectory for a person with an intellectual disability remains limited."

The report examines four key areas to determine how a new path can be forged for people with intellectual disabilities to be included in all aspects of society:

- Early family engagement to support high expectations for students with disabilities;
- Federal education policies and enforcement strategies to end segregation in schools;
- Transition to adulthood as a critical timeframe for establishing paths to higher education and career development; and
- Self-determination and supported decision-making starting in early childhood and continuing throughout the individual's lifespan.

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Report to the President

Strengthening an Inclusive Pathway for People with Intellectual Disabilities
and Their Families

2016
Supported decision-making is often defined as an individual using a team of trusted people (e.g., friends, family members, advocates) to help them understand a situation and the choices they have so they may make their own informed decisions to the best of their ability (Dinerstein, 2011–2012; Quality Trust, 2013). In a specific situation, supported decision-making takes into account the diversity of decisions to be made and can adjust the support a person needs depending on the nature of a given decision.

Although guardianship is still prevalent, supported decision-making is increasingly used as an augmentation to guardianship or even an alternative in the United States (Kohn, Blumenthal, & Campbell, 2013). The UN Convention on the Rights of Persons with Disabilities recognizes supported decision-making as a means to ensure access to human and civil rights for persons with disabilities, and several states have passed laws studying and authorizing the use of supported decision-making (Blank & Martinis, 2015). Supported decision-making can provide individuals with ID the skills to live self-determined lives and to enjoy the rights afforded them as humans and as citizens (Kohn et al, 2013).

Decision-making and self-determination involve both opportunity and teachable skills. Young adults who receive instruction to increase self-determination exhibit better employment outcomes, increased independence in daily-life activities, and more extensive community integration than those who do not (Powers et al., 2012; Shogren et al., in press). Studies have indicated a positive relationship between self-determination and quality of life. One such study found that young adults with greater self-determination were more likely to want to manage their own money, be employed in competitive integrated settings, and live independently (Wehmeyer & Schwartz, 1997). Other studies have found that adults who exerted more self-determination were more likely to live independently, protect themselves from abuse, and have higher-paying jobs (Wehmeyer & Palmer, 2003; Kehemka, Hickson, & Reynolds, 2005). Supported decision-making may increase self-determination and have a positive influence on an individual's quality of life.
Recommendations: Self-Determination and Supported Decision-Making

Recommendation #50: The U.S. Department of Health and Human Services (HHS-ACL) and the U.S. Department of Justice should monitor and study current guardianship laws in order to develop incentives for the adoption and expansion of augmentations and alternatives to guardianship, including supported decision-making.

Guardianship can be a problematic and a potentially abusive practice. More research must be conducted to determine the financial, political, and social incentives that maintain the system of guardianship. More research will also provide better data on the prevalence of guardianship and the monitoring that is or is not in place to protect people with guardians from abuse. In order for courts and providers to make informed decisions about guardianship and the use of alternatives such as supported decision-making, data regarding the use and outcomes of guardianship are necessary. As guardianship can severely limit an individual’s civil rights, sound information is necessary for those in the position to determine whether a person is assigned a guardian. Research also should be conducted on the potential reduction or elimination of guardianship and the impact such a shift may have on those currently under guardianship.

Recommendation #51: The Administration for Community Living (ACL), in collaboration with the Administration on Children, Youth, and Families (ACYF), should support the development and continued use of systems for sharing information about supported decision-making and alternatives to guardianship for individuals with intellectual disabilities, as well as for those who are aging.

As new data and information emerge about best practices in supported decision-making, that information must become readily accessible and shared with families, courts, school personnel, and service providers. Organizations such as the National Resource Center for Supported Decision-Making (NRC-SDM) are leading and coordinating efforts to make supported decision-making a recognized alternative or augmentation to guardianship (Blank & Martinis, 2015). The NRC-SDM is acting as a clearinghouse for information on supported decision-
making, conducting research on best practices in supported decision-making, and establishing services, such as a website for families, self-advocates, and government officials, to share information and coordinate efforts in promoting supported decision-making. ACL should collaborate with NRC-SDM to ensure that information about supported decision-making is widely available.

**Recommendation #52: The Office of Special Education and Rehabilitation Services (OSERS) and the Administration for Community Living (ACL) should jointly promote and distribute information about supported decision-making and self-determination as methods to engage individuals with intellectual disabilities in their own lives and exercise their rights throughout their lives.**

The OSERS and the ACL should work jointly to disseminate information about self-determination skill development and supported decision-making for people with ID throughout their lives. This dissemination should frame decision-making and self-determination as basic human rights and as a natural part of the human experience. To improve the trajectory of inclusion for individuals with ID, they should be supported in developing such skills as early as possible. Professionals (e.g., teachers, child care providers, personal care attendants) should be knowledgeable about self-determination and supported decision-making skills and should provide opportunities for children and young people with ID to develop those skills.

Likewise, those in a position to make decisions about guardianship for people with ID should have access to information about alternatives. In a study exploring the awareness perception of guardianship and its alternatives among educators, students with disabilities, and parents, it was found that almost all parties were aware of the nature and process of guardianship but few were aware of any alternatives, such as supported decision-making (Millar, 2007). The ACL and the OSERS should put in place strategies to provide guardianship decision-makers, such as judges, court officials, social workers, and transition specialists, with information about alternatives to guardianship.
Recommendation #53: The U.S. Departments of Education, Labor, and Health and Human Services should include in their personnel development grant programs requirements for education about supported decision-making and guardianship.

For all competitive grants related to pre-service and professional development in each of the three departments, grantees should be required to provide evidence-based instruction about supported decision-making and its outcomes related to autonomy, self-determination, and quality of life. Likewise, instruction should be required about the potential abuses and negative outcomes associated with guardianship.

Recommendation #54: The U.S. Department of Justice should consider including a competitive preference for its Bureau of Justice Assistance competitive grant programs to expand the knowledge of court officers about supported decision-making and guardianship.

The Department of Justice, through its Bureau of Justice Assistance competitive grant programs, should offer a preference for applicants who include evidence-based instruction for judges and court officers about supported decision-making and its outcomes related to autonomy, self-determination, and quality of life. Likewise, instruction should be required about the potential abuses and negative outcomes associated with guardianship.

Recommendation #55: The U.S. Department of Education should require, as part of the requirements for reporting data for IDEA Indicator 13, that the notice provided to families and youth with disabilities leading up to the age of majority include robust information about the implications of guardianship and options for supported decision-making.

The U.S. Department of Education should include in its reporting requirements concerning transition activities the mandate for states and local school districts to supply data regarding the type of information they provide to families and youth with disabilities about shared decision-making and the implications of partial and full guardianship. The Department should use the most up-to-date information generated by the National Institute on Disability,
Independent Living, and Rehabilitation Research (NIDILRR), the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), and the National Institute on Aging (NIA) about supported decision-making. The Department should also provide guidance about the quality of information to be shared. The percentage of families and students with disabilities receiving such information should be reported annually.

The members of the President's Committee for People with Intellectual Disabilities are hopeful that this Report will provide a strategy for strengthening federal policies in the areas of: family engagement, education, transition, and self-determination and supported decision-making to place people with intellectual disabilities on a new trajectory to full inclusion and access to opportunities for the highest quality of life.
AN ACT TO AMEND TITLE 16 OF THE DELAWARE CODE RELATING TO MEDICAL MARIJUANA OIL

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF DELAWARE:

Section 1. Amend § 4904A, Title 16, Delaware Code by making deletions as shown by strike through and insertions as shown by underline as follows:

§4904A Limitations

(a) This chapter does not authorize any person to engage in, and does not prevent the imposition of any civil, criminal, or other penalties for engaging in, the following conduct:

(2) Possessing Except as provided in subsection (b) of this section, possessing marijuana, or otherwise engaging in the medical use of marijuana:

a. In a school bus;

b. On the grounds of any preschool or primary or secondary school; or

c. In any correctional facility.

d. In any health care or treatment facility operated by the Department or funded contractually through the Department.

(b) School exceptions. Notwithstanding subsection (a) of this section, a designated caregiver registered pursuant to §4908A of this Title may possess for the purpose of administering, and may administer to a minor qualifying patient medical marijuana oil in a school bus and on the grounds or property of the preschool, or primary or secondary school in which a minor qualifying patient is enrolled. The designated caregiver shall not be a school nurse or other school employee hired or contracted by a school unless he or she is a parent or legal guardian of the minor qualifying patient, and said parent...
or legal guardian possesses no more than the number of dose(s) prescribed per day of medical marijuana oil which is kept at all times on their person. Provided further, this exception shall only apply within the physical boundaries of the State of Delaware.
to assisting the member in reaching his/her goals as stated in the plan of care.

3.6.4 Clinical Practice Guidelines

3.6.4.1 The Contractor’s care coordination program shall utilize evidence-based practice guidelines.

3.6.4.2 The Clinical care coordination program shall be described and included in the contractor’s utilization management program description.

3.6.5 Informing and Educating Members

3.6.5.1 The Contractor shall inform all members of the availability of care coordination program activities at all levels and how to access and use care coordination program services.

3.6.6 Informing and Educating Providers

3.6.6.1 The Contractor shall inform providers regarding the operation and goals of the care coordination programs at all levels. Providers shall be given instructions on how to access appropriate services as well as the benefits to the provider.

3.6.7 Care Coordination System Capabilities

3.6.7.1 The Contractor shall maintain and operate a centralized information system necessary to conduct risk stratification. Systems recording program documentation shall include the capability of collecting and reporting short term and intermediate outcomes such as member behavior change. The system shall be able to collect and query information on individual members as needed for follow-up confirmations and to determine intervention outcomes.

3.6.7.2 The Contractor shall work with DMMA to develop Contractor system capacity around promoting provider level care coordination services.

3.6.8 Evaluation

3.6.8.1 The Contractor shall submit the care coordination reports specified in Section 3.21 of this Contract.

3.7 CASE MANAGEMENT FOR DSHP PLUS LTSS MEMBERS

3.7.1 Administrative Standards

3.7.1.1 General
3.7.1.1.1 The Contractor shall provide case management to DSHP Plus LTSS members. This Section of the Contract does not apply to DSHP members nor to DSHP Plus members who are not DSHP Plus LTSS members.

3.7.1.2 Case Management Staff Qualifications

3.7.1.2.1 The Contractor shall ensure that individuals hired as case managers are either:

3.7.1.2.1.1 Individuals with a Bachelor's degree in health, human, social work or education services with one or more years of qualifying experience; or a high school degree or equivalent and three years of qualifying experience with case management of the aged, including management of behavioral health conditions, or persons with physical or developmental disabilities, or HIV/AIDS population; or

3.7.1.2.1.2 Licensed as an RN; or LPN with two years of qualifying experience with appropriate supervision in accordance with Delaware law (see 24 DE Admin Code 1900).

3.7.1.2.2 The Contractor shall ensure that case managers have:

3.7.1.2.2.1 Experience interviewing and assessing member needs;

3.7.1.2.2.2 Knowledge and experience regarding caseload management and casework practices;

3.7.1.2.2.3 Knowledge regarding determining eligibility for DHSS programs;

3.7.1.2.2.4 Knowledge regarding Federal and State law as it applies to DHSS programs;

3.7.1.2.2.5 The ability to effectively solve problems and locate community resources;

3.7.1.2.2.6 The ability to collaborate with Caregivers, involved State agency representatives and providers;

3.7.1.2.2.7 Good interpersonal skills;

3.7.1.2.2.8 Fundamental background in cultural and socio-economic diversity; and

3.7.1.2.2.9 Knowledge of the needs and service delivery system for all populations in the case manager's caseload.
3.7.1.4.5 Cultural Competency;
3.7.1.4.6 Medical/behavioral health issues; and/or
3.7.1.4.7 Medications – side effects, contraindications and polypharmacy issues.

3.7.1.4.5 Training may be provided by external sources, for example by:
3.7.1.4.5.1 Consumer advocacy groups;
3.7.1.4.5.2 Providers (for example, medical or behavioral health); or
3.7.1.4.5.3 Accredited training agencies.

3.7.1.4.6 The Contractor shall ensure that a staff person(s) is designated as the expert(s) on housing, education and employment issues and resources. This expert must assist case managers with up-to-date information designed to aid members in making informed decisions about their independent living options.

3.7.1.5 Caseload Management

3.7.1.5.1 The Contractor shall have an adequate number of qualified and trained case managers to meet the needs of DSHP Plus LTSS members.

3.7.1.5.2 The Contractor must ensure that newly Enrolled DSHP Plus LTSS members are assigned to a case manager immediately upon Enrollment. The case manager assigned to a special subpopulation (e.g., members with HIV/AIDS or ABI or PROMISE participants) must have experience or training in case management techniques for such population.

3.7.1.5.3 The Contractor must maintain case manager staffing ratios of:

- 3.7.1.5.3.1 1:120 for members living in nursing facilities;
- 3.7.1.5.3.2 1:60 for members receiving HCBS (living in their own home or assisted living facility); and
- 3.7.1.5.3.3 1:30 for members receiving services under the Money Follows the Person (MFP) program.

3.7.1.5.4 If the Contractor utilize the services of agencies to provide case management services for DSHP Plus LTSS members with HIV/AIDS who meet acute hospital LOC:
3.7.1.5.4.1 The agency’s case manager staffing ratio must be 1:60 members; and

3.7.1.5.4.2 The Contractor’s case manager staffing ratios must be 1:100 members.

3.7.1.5.5 The Contractor shall ensure that case management is provided at a level dictated by the complexity and required needs of the member, including coordination needed to implement a comprehensive plan of care that addresses all of the member’s needs.

3.7.1.5.6 The Contractor shall ensure that each case manager’s caseload does not exceed a weighted value of 120. The following formula represents the maximum number of members allowable per case manager:

3.7.1.5.6.1 For nursing facility members, a weighted value of 1 is assigned. Case managers may have up to 120 institutionalized members (120 x 1 = 120).

3.7.1.5.6.2 For HCBS members (living in their own home or assisted living facility), a weighted value of 2 is assigned. Case managers may have up to 60 HCBS members (60 x 2 = 120).

3.7.1.5.6.3 For MFP members, a weighted value of 4 is assigned. Case managers may have up to 30 MFP members (30 x 4 = 120).

3.7.1.5.6.4 If a mixed caseload is assigned, there can be no more than a weighted value of 120. The following formula is to be used in determining a case manager’s mixed caseload:

\[
3.7.1.5.6.4.1 \quad \text{(# of NF members x 1) + (# of HCBS members x 2) + (# of MFP members x 4) = 120 or less}
\]

3.7.1.5.6.5 The Contractor must receive authorization from the State prior to implementing caseloads whose values exceed those specified above. The Contractor may establish lower caseload sizes at its discretion without prior authorization from the State.

3.7.1.6 Accessibility

3.7.1.6.1 The Contractor shall provide members and/or member representatives with adequate information in order to be able to contact their case manager or the Contractor’s member services information line for assistance, including what to do in cases of emergencies and/or after hours.
Preserving the Right to Self-determination: Supported Decision-Making

By Aaron Bishop, Commissioner, Administration for Intellectual and Developmental Disabilities, and Edwin Walker, Deputy Assistant Secretary for Aging

For many years, state courts have routinely assigned guardians to people with intellectual and developmental disabilities as they became adults. Older adults with dementia-related disorders also frequently have been assigned guardians.

The trouble with guardianship is that it is a legal process. A court deems a person incapacitated or legally incompetent and assigns a substitute decision-maker for that person. Guardianship laws vary by state, but in some states, guardians are given the authority to make all financial, legal, and personal decisions on behalf of another person. Essentially, the person can lose all of his or her rights to independence, autonomy, and decision-making.

This approach assumes that people with disabilities and older adults are incapable of making decisions. That is simply not the case.

The goal of the Administration for Community Living is to maximize the independence and well-being of older adults and people with disabilities. We are proud to be a leader in exploring alternatives to guardianship. We believe supported decision-making poses the most promising and flexible model.

Supported decision-making starts with the assumption that people with intellectual and developmental disabilities and older adults with cognitive impairment should retain choice and control over all the decisions in their lives. It is not a program. Rather, it is a process of working with the person to identify where help is needed and devising an approach for providing that help. Different people need help with different types of decisions. For some, it might be financial or health care decisions. Others may need help with decisions surrounding reproductive rights or voting. Some may need help with many types of decisions, while others need help with only one or two.

The solutions also are different for each person. Some people need one-on-one support and discussion about the issue at hand. For others, a team approach works best. Some people may benefit from situations being explained pictorially. With Supported decision-making the possibilities are endless.

The key is that the process is centered on the person to whom the decisions apply, and it enables the person to make decisions based on his or her wants and preferences. Supported decision-making keeps control in the hands of the individual, while providing assistance in specific ways and in specific situations that are useful to the person.

We know on a case-by-case basis and anecdotally that supported decision-making works, and it appears to have the potential to provide a significant improvement to current guardianship arrangements. However, it has not been formally tested, which can make it difficult for states to adopt the practice.

To address that challenge, the Administration on Intellectual and Developmental Disabilities and the Administration on Aging, two program components of the Administration for Community Living, jointly awarded a cooperative agreement to Quality Trust for Individuals with Disabilities to build a national training, technical assistance, and resource center to explore and develop supported decision-making as an alternative to guardianship. The resource center will gather and disseminate data on the various ways in which supported decision-making is being implemented and generate research in the area. Our goal is that
the information collected during the period of this cooperative agreement will lead to a model that will help states as they consider alternatives to guardianship.

We are excited by the possibilities this work may generate. It is another step toward ensuring all people are treated with dignity and respect throughout their lives. It is another step toward a vision for the future that includes a collective recognition that the right to self-determination and independence are fundamental for everyone. And ultimately, it offers the promise of new opportunities for people with disabilities and older adults to live and thrive in the communities of their choice.

Update: A Message from Commissioner Bishop

February 13, 2015

Thank you to all our readers who joined this discussion and shared their personal perspectives. The range and diversity of stories, experiences, and responses shows there is no one-size-fits-all solution to this important issue. Many of the concerns shared here highlight exactly the sort of questions that the National Resource Center for Supported Decision Making seeks to explore.

As Deputy Assistant Secretary Walker and I noted in our blog, when it comes to supported decision-making, no two situations are exactly alike. The Administration for Community Living (ACL) recognizes that people with disabilities and older Americans sometimes experience challenges in understanding and communicating their preferences and needs—and, as your stories illustrate, family members and caregivers often play a critical role in ensuring that those preferences are honored and needs are met. Your stories also demonstrate the dangers that can arise when guardianship is viewed as the default option for those who only need support with making a few decisions.

ACL promotes the concept of supported decision-making not because it is the only option, but because it offers flexibility to provide as much assistance as needed—including total assistance, when that is appropriate—while also ensuring that the right to self-determination is preserved for each individual.

We thank you again for your contributions to this important discussion and hope you will keep the comments coming. The feedback you provide will help us think about, and talk about, this issue more clearly going forward.

Replies

<table>
<thead>
<tr>
<th>Name</th>
<th>Date</th>
<th>Comment</th>
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<tbody>
<tr>
<td>Silvia</td>
<td>January 29, 2015</td>
<td>This is a great and timely project—thank you. Just a couple of additional factors that would be great to consider as research is done. 1st, consider how the various options for partial decision-making authority impact on the person with a disability and those people in their lives who can/do provide assistance and decision support or actual transferred decision-making. That is, does a family member have to work through 2, 4 or 10 different forms and authorization processes for different agencies, government levels, and topical areas to avoid being an overall legal guardian? Does each agency or authority ignore other kinds of authorizations? 2nd, consider the impact of additional factors that arise in the context of the kind of passive enrollment processes that are commonly occurring in Medicare and Medicaid dual-eligible integration pilots, for example, where PWD are enrolled into managed care plans unless they hear otherwise from a beneficiary or &quot;authorized representative.&quot; Thanks much.</td>
</tr>
<tr>
<td>Cathy</td>
<td>January 29, 2015</td>
<td>My son self determines everything about his life. He is labeled ID. I could not imagine his life if someone else chose for him. He is well rounded and not pigeon holed.</td>
</tr>
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Guardianship can be a problematic and a potentially abusive practice. More research must be conducted to determine the financial, political, and social incentives that maintain the system of guardianship. More research will also provide better data on the prevalence of guardianship and the monitoring that is or is not in place to protect people with guardians from abuse. In order for courts and providers to make informed decisions about guardianship and the use of alternatives such as supported decision-making, data regarding the use and outcomes of guardianship are necessary. As guardianship can severely limit an individual’s civil rights, sound information is necessary for those in the position to determine whether a person is assigned a guardian. Research also should be conducted on the potential reduction or elimination of guardianship and the impact such a shift may have on those currently under guardianship.

Recommendation #51: The Administration for Community Living (ACL), in collaboration with the Administration on Children, Youth, and Families (ACYF), should support the development and continued use of systems for sharing information about supported decision-making and alternatives to guardianship for individuals with intellectual disabilities, as well as for those who are aging.

As new data and information emerge about best practices in supported decision-making, that information must become readily accessible and shared with families, courts, school personnel, and service providers. Organizations such as the National Resource Center for Supported Decision-Making (NRC-SDM) are leading and coordinating efforts to make supported decision-making a recognized alternative or augmentation to guardianship (Blank & Martinis, 2015). The NRC-SDM is acting as a clearinghouse for information on supported decision-
making, conducting research on best practices in supported decision-making, and establishing services, such as a website for families, self-advocates, and government officials, to share information and coordinate efforts in promoting supported decision-making. ACL should collaborate with NRC-SDM to ensure that information about supported decision-making is widely available.

Recommendation #52: The Office of Special Education and Rehabilitation Services (OSERS) and the Administration for Community Living (ACL) should jointly promote and distribute information about supported decision-making and self-determination as methods to engage individuals with intellectual disabilities in their own lives and exercise their rights throughout their lives.

The OSERS and the ACL should work jointly to disseminate information about self-determination skill development and supported decision-making for people with ID throughout their lives. This dissemination should frame decision-making and self-determination as basic human rights and as a natural part of the human experience. To improve the trajectory of inclusion for individuals with ID, they should be supported in developing such skills as early as possible. Professionals (e.g., teachers, child care providers, personal care attendants) should be knowledgeable about self-determination and supported decision-making skills and should provide opportunities for children and young people with ID to develop those skills.

Likewise, those in a position to make decisions about guardianship for people with ID should have access to information about alternatives. In a study exploring the awareness perception of guardianship and its alternatives among educators, students with disabilities, and parents, it was found that almost all parties were aware of the nature and process of guardianship but few were aware of any alternatives, such as supported decision-making (Millar, 2007). The ACL and the OSERS should put in place strategies to provide guardianship decision-makers, such as judges, court officials, social workers, and transition specialists, with information about alternatives to guardianship.
Recommendation #53: The U.S. Departments of Education, Labor, and Health and Human Services should include in their personnel development grant programs requirements for education about supported decision-making and guardianship.

For all competitive grants related to pre-service and professional development in each of the three departments, grantees should be required to provide evidence-based instruction about supported decision-making and its outcomes related to autonomy, self-determination, and quality of life. Likewise, instruction should be required about the potential abuses and negative outcomes associated with guardianship.

Recommendation #54: The U.S. Department of Justice should consider including a competitive preference for its Bureau of Justice Assistance competitive grant programs to expand the knowledge of court officers about supported decision-making and guardianship.

The Department of Justice, through its Bureau of Justice Assistance competitive grant programs, should offer a preference for applicants who include evidence-based instruction for judges and court officers about supported decision-making and its outcomes related to autonomy, self-determination, and quality of life. Likewise, instruction should be required about the potential abuses and negative outcomes associated with guardianship.

Recommendation #55: The U.S. Department of Education should require, as part of the requirements for reporting data for IDEA Indicator 13, that the notice provided to families and youth with disabilities leading up to the age of majority include robust information about the implications of guardianship and options for supported decision-making.

The U.S. Department of Education should include in its reporting requirements concerning transition activities the mandate for states and local school districts to supply data regarding the type of information they provide to families and youth with disabilities about shared decision-making and the implications of partial and full guardianship. The Department should use the most up-to-date information generated by the National Institute on Disability,
Independent Living, and Rehabilitation Research (NIDILRR), the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), and the National Institute on Aging (NIA) about supported decision-making. The Department should also provide guidance about the quality of information to be shared. The percentage of families and students with disabilities receiving such information should be reported annually.

The members of the President’s Committee for People with Intellectual Disabilities are hopeful that this Report will provide a strategy for strengthening federal policies in the areas of: family engagement, education, transition, and self-determination and supported decision-making to place people with intellectual disabilities on a new trajectory to full inclusion and access to opportunities for the highest quality of life.
Pre-Employment Inquiries and Medical Questions & Examinations

The ADA places restrictions on employers when it comes to asking job applicants to answer medical questions, take a medical exam, or identify a disability.

An employer may not ask a job applicant, for example, if he or she has a disability (or about the nature of an obvious disability). An employer also may not ask a job applicant to answer medical questions or take a medical exam before making a job offer.

An employer may ask a job applicant whether they can perform the job and how they would perform the job. The law allows an employer to condition a job offer on the applicant answering certain medical questions or successfully passing a medical exam, but only if all new employees in the same job have to answer the questions or take the exam.

Once a person is hired and has started work, an employer generally can only ask medical questions or require a medical exam if the employer needs medical documentation to support an employee’s request for an accommodation or if the employer has reason to believe an employee would not be able to perform a job successfully or safely because of a medical condition.

The law also requires that the employers keep all medical records and information confidential and in separate medical files.
ADA Violated When Employer Responds to State Subpoena and Discloses Former Employee’s Medical Records

By Joseph J. Lazzarotti on March 23, 2011

The confidentiality of medical records requirement under the Americans with Disability Act (ADA) is violated when an employer discloses a current or former employee’s medical records in response to a state court subpoena absent the employee’s release or some other exception under the ADA, the Equal Employment Opportunity Commission (EEOC) recently held in Bennett v. U.S. Postal Serv., 2011 WL 244217 (E.E.O.C.), Jan. 11, 2011.

Companies frequently receive requests for information about current and former employees. These requests often come in the form of an attorney’s demand letter or a subpoena and apply to the individual’s medical records. Those receiving such requests typically feel compelled to respond without taking the time to think through issues such as:

- what kind of information in contained within the files being requested;
- what specific statutory or regulatory protections apply for some or all of the information being requested (see below);
- is a response appropriate without an authorization of the individual or giving an individual an opportunity to object;
- is a court order needed for some or all of the information being requested; and
- what safeguards should be taken to ensure the disclosure is secure.

As we have reported previously, failing to think through these issues can be a costly trap for the unwary.

EEOC Analysis
In the Bennett decision cited above, the EEOC sets out the basic ADA requirements concerning confidentiality of employee medical records:

"Title I of the [ADA] requires that all information obtained regarding the medical condition or history of an applicant or employee must be maintained on separate forms and in separate files and must be treated as confidential medical records. [Citations omitted]. These requirements also extend to medical information that an individual voluntarily discloses to an employer. [Citations omitted]. The confidentiality obligation imposed on an employer by the ADA remains regardless of whether an applicant is eventually hired or the employment relationship ends. [Citations omitted]. These requirements apply to confidential medical information from any applicant or employee and are not limited to individuals with disabilities. [Citations omitted].

The decision goes on to explain the general exceptions to these requirements:

- supervisors and managers may be informed regarding necessary restrictions on the work or duties of the employee and necessary accommodations;
- first aid and safety personnel may be informed, when appropriate, if the disability might require emergency treatment;
- government officials investigating compliance with this part shall be provided relevant information on request;
- employers may disclose medical information to state workers' compensation offices, state second injury funds, workers' compensation insurance carriers, and to health care professionals when seeking advice in making reasonable accommodation determinations; and
- employers may use medical information for insurance purposes.

The EEOC found that the Postal Service's disclosure of Mr. Bennett's medical records in response to the subpoena issued by the Galveston County 405th District Court did not fall into one of these exceptions. The EEOC held that while the ADA allows an employer to comply with the requirements of another federal statute or rule, even if in conflict with the ADA, "it is not a valid defense to argue that the [Postal Service's] actions were required by state law," (emphasis added) unless one of the ADA exceptions applied. The Commission also noted the subpoena in this case was signed and issued by the Deputy Clerk, and did not qualify as an
"order" for purposes of the Privacy Act of 1974, on which the Agency attempted to rely to permit the disclosure.

Because of this violation of the ADA, the EEOC ordered the Postal Service (i) to start an investigation into compensatory and other damages that may be due to Mr. Bennett, (ii) to conduct training concerning the ADA’s confidentiality requirements, and (iii) to prepare a report regarding corrective action. The Postal Service also may be responsible for Mr. Bennett’s attorneys’ fees, among other things.

**Is the ADA the only concern?**

In short, no, the ADA is only one protection for medical and other personal information that could trigger exposure for a company that improperly discloses such information. There is an increasing array of federal and state laws that need to be examined, as appropriate, before responding to a request:

- **GINA**: Regulations issued under Title II (GINA’s employment provisions) provide that employers that possess genetic information must maintain the information in confidence and may not disclose that information except in limited circumstances, such as (i) at the request of the employee, (ii) in response to a court order, (iii) to respond to a request from a government official investigating GINA compliance, or (iv) in support of an employee’s FMLA certification. The preamble to the GINA regulations provides that the court order exception "does not allow disclosures in other circumstances during litigation, such as in response to discovery requests or subpoenas that are not governed by an order specifying that genetic information must be disclosed. Thus, a covered entity’s refusal to provide genetic information in response to a discovery order, subpoena, or court order that does not specify that genetic information must be disclosed is consistent with the requirements of GINA." Additionally, the individual whose genetic information is disclosed may need to be notified.

- **HIPAA**: The privacy regulations under HIPAA likewise generally prohibit the disclosure of "protected health information" except in limited circumstances. HIPAA regulation 45 CFR 164.512 (e), among other exceptions to the general rule, provides an exception for disclosures in connection with administrative and judicial proceedings. But one of the first questions to ask is whether the information being sought is "protected health information." Very often, employee medical information in a personnel or medical file is not, in the hands of the employer, protected health information subject to HIPAA.

- **42 USC Part 2**: Federal law provides very stringent protection for records relating to substance abuse treatment at certain federally funded facilities.
- **State law**: Many states have laws protecting certain classes of medical records from disclosure without taking appropriate safeguards to address confidentiality. This includes *application of the physician-patient privilege*, as well as statutes and regulations dealing with specific types of information, such as mental health records.

Because of these issues, businesses should develop a clear policy and procedure to direct employees on how to respond when they receive these requests.
Providing Early Intervention Services in Natural Environments

Updated, October 2016
A legacy resource from NICHCY

Early intervention services are to be provided in natural environments to the maximum extent appropriate for the child and for the EI service itself.

So—what’s considered a “natural environment”? What isn’t? This webpage focuses upon answering these questions and on connecting you with resources of additional information and best practice.

- IDEA’s definition of “natural environment”
- Who decides where?
- Based on what?
- What must be included in the IFSP?
- Two points from the Department of Education
- Resources of more information

IDEA’s Definition of “Natural Environment”

Part C of the Individuals with Disabilities Education Act (IDEA) requires that eligible infants and toddlers with disabilities receive needed early intervention services in natural environments to the maximum extent appropriate. The 2011 regulations for Part define the term as follows:

§303.26 Natural environments.
Natural environments means settings that are natural or typical for a same-aged infant or toddler without a disability, may include the home or community settings, and must be consistent with the provisions of §303.126.

That’s a straightforward, easily understood definition—with the exception of how it ends ("... must be consistent with the provisions of §303.126"). What might the provisions of §303.126 require?

Let’s have a look. Here they are:

§303.126 Early intervention services in natural environments.

Each system must include policies and procedures to ensure, consistent with §§303.13(a)(8) (early intervention services), 303.26 (natural environments), and 303.344(d)(1)(ii) (content of an IFSP), that early intervention services for infants and toddlers with disabilities are provided—

(a) To the maximum extent appropriate, in natural environments; and

(b) In settings other than the natural environment that are most appropriate, as determined by the parent and the IFSP Team, only when early intervention services cannot be achieved satisfactorily in a natural environment.

Combining these two sets of provisions makes it clear that early intervention services:

- must be provided in settings that are natural or typical for a same-aged infant or toddler without a disability to the maximum extent appropriate;
- may be provided in other settings only when the services cannot be achieved satisfactorily in a natural environment.

Who Decides Where Services Will Be Provided?

The Part C regulations also make it clear that the IFSP team determines the appropriate setting for providing early intervention services to a child or toddler. The IFSP team may determine that a service will not be provided in a natural environment only "when early intervention services cannot be achieved satisfactorily in a natural environment."

Note | IFSP team refers broadly to the group of people who write the child’s individualized family service plan (IFSP). More specifically, as described in the Part C regulations:
• The child’s parents are members of the IFSP team. They may invite other family members to participate on the team as well (if it’s feasible to do so). They may also request an advocate or person from outside the family to participate on the team.
• The IFSP team must include two or more individuals from separate disciplines or professions, one of which must be the family’s service coordinator.
• The IFSP team must also include a person or persons directly involved in conducting the evaluations and assessments of the child and family.
• As appropriate, people who will be providing early intervention services to the child may also serve on the IFSP team. (§303.343)

This, then, is the group of well-informed individuals that makes the decision as to where early intervention services will be provided to the baby or toddler.

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On What Basis Does the Team Decide the Setting?

The short answer | The IFSP team decides where each EI service will be provided based on the measurable results or measurable outcomes expected to be achieved by the child. Those results or outcomes have been identified by the IFSP team and listed in the IFSP.

The longer answer | Again, the Part C regulations provide the necessary guidance. At §303.344(d)(1)(ii)(B), the regulations state:

(B) The determination of the appropriate setting for providing early intervention services to an infant or toddler with a disability, including any justification for not providing a particular early intervention service in the natural environment for that infant or toddler with a disability and service, must be—

(1) Made by the IFSP Team (which includes the parent and other team members);

(2) Consistent with the provisions in §§303.13(a)(8), 303.26, and 303.126; and

(3) Based on the child’s outcomes that are identified by the IFSP Team in paragraph (c) of this section... [emphasis added]

An example | The Department of Education provides an example of how it may not always be practicable or appropriate for an infant or toddler with a disability to receive an early intervention service in the natural environment based either on the nature of the service or the child’s specific outcomes. The Department states:
For example, the IFSP Team may determine that an eligible child needs to receive speech services in a clinical setting that serves only children with disabilities in order to meet a specific IFSP outcome. When the natural environment is not chosen with regard to an early intervention service, the IFSP Team must provide, in the IFSP, an appropriate justification for that decision. (76 Fed. Reg. at 60205)

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What Must Be Included about Natural Environments in the Child’s IFSP?

The Part C regulations indicate that the IFSP must include:

…A statement that each early intervention service is provided in the natural environment for that child or service to the maximum extent appropriate …

or…

a justification as to why an early intervention service will not be provided in the natural environment. [§303.344(d)(1)(ii)(A)]

If the IFSP team determines that an early intervention service will not be provided in the natural environment, it must document in the IFSP the justification for why not— in other words, “why the alternative service setting is needed for the child to meet the developmental outcomes identified for the child in his or her IFSP” (76 Fed. Reg. at 60205).

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Two Points from the Department of Education

When the Department of Education released the 2011 Part C implementing regulations, it included the often fascinating Analysis of Comments and Changes. The Department's discussion of “natural environments” includes two very interesting and illuminating observations we'd like to share with you.

Why not include a list of settings considered “natural environments” and those not considered “natural environments”? | The Department declined to add a fuller list of settings that may be considered (or would not be considered) “natural environments.” The current regulations only mention that natural environments “may include home and community settings.” Why did the Department decline including a fuller list? According to the Department:
“It would not be appropriate or practicable to include a list of every setting that may be the natural environment for a particular child or those settings that may not be natural environments in these regulations.

In some circumstances, a setting that is natural for one eligible child based on that child’s outcomes, family routines, or the nature of the service may not be natural for another child....

[The decision about whether an environment is the natural environment is an individualized decision made by an infant’s or toddler’s IFSP Team, which includes the parent...]” (76 Fed. Reg. at 60157-60158)

Are clinics, hospitals, or a service provider’s office considered “natural environments”? A very good question, you must admit! Here’s the Department’s response:

We appreciate the commenters’ requests for clarification as to whether clinics, hospitals, or a service provider’s office may be considered the natural environment in cases when specialized instrumentation or equipment that cannot be transported to the home is needed.

Natural environments mean settings that are natural or typical for an infant or toddler without a disability.... We do not believe that a clinic, hospital or service provider’s office is a natural environment for an infant or toddler without a disability; therefore, such a setting would not be natural for an infant or toddler with a disability.

However, §303.344(d)(1) requires that the identification of the early intervention service needed, as well as the appropriate setting for providing each service to an infant or toddler with a disability, be individualized decisions made by the IFSP Team based on that child’s unique needs, family routines, and developmental outcomes. If a determination is made by the IFSP Team that, based on a review of all relevant information regarding the unique needs of the child, the child cannot satisfactorily achieve the identified early intervention outcomes in natural environments, then services could be provided in another environment (e.g. clinic, hospital, service provider’s office). In such cases, a justification must be included in the IFSP... (76 Fed. Reg. at 60158)

Resources of More Information on Natural Environments

From the ECTA Center, the expert! | Early intervention services in natural environments. A very sweet resource page! Be sure to visit and explore it.  
http://ectacenter.org/topics/eiservices/eiservices.asp
7 key principles: Looks like/Doesn’t look like.
http://www.nectac.org/~pdfs/topics/families/Principles_LooksLike_DoesntLookLike3_11_08.pdf

Early intervention in natural environments: A 5-component model.

Providing early intervention services in natural environments - Concerns and tips.
http://hpcswf.com/downloads/Providing%20EI%20Services%20in%20NE.pdf

From selected National Professional Associations.

What the American Physical Therapy Association has to say.

Natural environments for infants and toddlers who are deaf or hard of hearing and their families.
From ASHA, the American Speech-Language-Hearing Association.
http://www.asha.org/aud/Natural-Environments-for-Infants-and-Toddlers/

From the American Occupational Therapy Association.
http://www.aota.org/-/media/Corporate/Files/Practice/Children/AOTA-Advisory-on-Primary-Provider-inEI.pdf

Would you like to visit another page in the Early Intervention Suite of pages?

- Overview of Early Intervention
- Services in Your State for Infants and Toddlers
- Parent Participation
- Parent Notification and Consent
- Writing the IFSP for Your Child
- Providing Services in Natural Environments (you’re already here)
- Transition to Preschool
- Public Awareness & the Referral System
- Early Intervention, Then and Now
- Who’s Who in Early Intervention
- Effective Practices in Early Intervention
- Key Terms to Know in Early Intervention

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Early Intervention (Part C of IDEA)

At Wrightslaw, we receive many questions from parents, teachers, therapists, and health care providers about early intervention services for children. **What is early intervention?** What does it include? Does my child qualify? What should I do if I am not happy with evaluations, programs or services? **What is Part C?** Is it the same as Part B but for younger children? Is an IFSP different from an IEP? These are just a few of the questions people ask.

If you are a parent, you need to educate yourself about your child's disability or delay, effective educational methods, different types of therapies and medical treatments, and how to present your child's problems and needs to school staff so they want to help.

On this page, you will find many resources to help you along the way. Your path to learning starts here.

**New! US DOE Policy Statement, 09/14/15** on Inclusion of Children with Disabilities in Early Childhood Programs. Clarifies US DOE position that all young children with disabilities should have access to inclusive high-quality early childhood programs, where they are provided with individualized and appropriate support in meeting high expectations.

**OSEP Dear Colleague Letter, 07/06/15**, addresses concerns about speech-language services for children with autism spectrum disorder (ASD), clarifying requirements of the IDEA related to the provision of services for children with disabilities, including children with ASD [including infants and toddlers in Part C with IFSPs]. Clarification of OSEP's concern that SLPs and other appropriate professionals may not be included in evaluation and eligibility determinations.

**What is Early Intervention?**

Early intervention is the process of providing services, education and support to young children who are deemed to have an established condition, those who are evaluated and deemed to have a diagnosed physical or mental condition (with a high probability of resulting in a developmental delay), an existing delay or a child who is at-risk of developing a delay or special need that may affect their development or impede their education. The purpose of early intervention is to lessen the effects of the disability or delay. Services are designed to identify and meet a child's needs in five developmental areas, including: physical development, cognitive development, communication, social or emotional development, and adaptive development.

Early intervention programs and services may occur in a variety of settings, with a heavy emphasis on **natural environments**. These programs and/or services are proven to be most effective when started as soon as the delay or disability is identified.

**Child Find** information and resources from Wrightslaw.

**Child Find** is a component of IDEA that requires states to identify, locate, and evaluate all children with disabilities, aged birth to 21, who are in need of early intervention or special education services.
The at-risk category depends on the state's eligibility determination process and whether it includes children who are at-risk. States are given the discretion of including children at-risk in their state plans.

Natural Environments

Part C of IDEA requires "to the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate." (34 CFR §303.12(b))

By definition, natural environments mean "settings that are natural or normal for the child's age peers who have no disabilities." (34 CFR §303.18)

The exception to the rule reads "the provision of early intervention services for any infant or toddler with a disability occurs in a setting other than a natural environment that is most appropriate, as determined by the parent and the individualized family service plan team, only when early intervention cannot be achieved satisfactorily for the infant or toddler in a natural environment."

The provision of early intervention services taking place in natural environments is not just a guiding principle or suggestion, it is a legal requirement.

Least Restrictive Environment (LRE) for Preschool. OSEP Letter, 02/29/12. This OSEP letter reiterates that the least restrictive environment (LRE) requirements in section 612(a)(5) of the IDEA apply to the placement of preschool children with disabilities. 20 USC §1412(a)(5). The statutory provision on LRE does not distinguish between school-aged and preschool-aged children and therefore, applies equally to all preschool children with disabilities.

Part C of IDEA: The Early Intervention Program for Infants and Toddlers with Disabilities

Congress established the Part C (Early Intervention) program in 1986 in recognition of "an urgent and substantial need" to:

- enhance the development of infants and toddlers with disabilities;
- reduce educational costs by minimizing the need for special education through early intervention;
- minimize the likelihood of institutionalization, and maximize independent living; and,
- enhance the capacity of families to meet their child's needs.

The Program for Infants and Toddlers with Disabilities (Part C of IDEA) is a federal grant program that assists states in operating a comprehensive statewide program of early intervention services for infants and toddlers with disabilities, ages birth through age 2 years, and their families. In order for a state to participate in the program it must assure that early intervention will be available to every eligible child and its family. Also, the governor must designate a lead agency to receive the grant and administer the program, and appoint an Interagency Coordinating Council (ICC), including parents of young children with disabilities, to advise and assist the lead agency. Currently, all states and eligible territories are participating in the Part C program. Annual funding to each state is based upon census figures of the number of children, birth through 2, in the general population.
In 2004, President Bush signed legislation reauthorizing IDEA. The current IDEA 2004 Statute (P.L. 108-446) for Part C (PDF) contain many requirements states have to meet, including specifying the minimum components of comprehensive statewide early intervention system. States have some discretion in setting the criteria for child eligibility, including whether or not to serve at risk children. As a result, definitions of eligibility differ significantly from state to state. States also differ concerning which state agency has been designated "lead agency" for the Part C program. In fact, statewide early intervention systems differ in many ways from state to state. (source)

Update: On September 28, 2011, the IDEA 2004 Part C Final Regulations governing the Early Intervention Program for Infants and Toddlers with Disabilities were published in the Federal Register. These regulations are effective on October 28, 2011. Regulations & Analysis of Comments and Changes (Commentary) were published in the Federal Register, Vol. 76, No. 188, September 28, 2011, p. 60140. PDF Format

Part C (Birth - 2 years old) IDEA 2004: Building the Legacy. U.S. Department of Education, Office of Special Education Programs’ (OSEP’s) Part C of the IDEA website to provide a "one-stop shop" for resources related to Part C.

Building the Legacy of our Youngest Children with Disabilities. Training Guide on Part C from the Center for Parent Information and Resources (CPIR), the legacy resource for NICHCY.

Evaluation and Assessments

Under IDEA, evaluation and assessments are to be provided at no cost to the parent. Evaluation refers to the process used by the multidisciplinary team (qualified people with training and experience in the areas of speech and language skills, physical abilities, hearing and vision, and other important areas of development) to find out whether or not your child is eligible for early intervention services. As part of the evaluation, the multidisciplinary team will observe, interact, and use other tools or methods to gather information on your child. These procedures will help the team find out how your child functions. The team will then meet with you to discuss whether the findings mean that your child is eligible for services under Part C.

Eligibility for Part C

Part C eligibility is determined by each state's definition of developmental delay and whether it includes children at risk for disabilities in the eligibility formula. An important part of the evaluation process for infants and toddlers (ages 0 - 36 months) includes informed clinical opinion of professionals experienced with the development of very young children. States have been given a lot of discretion for determining eligibility for entry into their programs. If your child is determined to be eligible, the next step is to create an IFSP.

The Individualized Family Service Plan (IFSP)

An Individualized Family Service Plan (IFSP) documents and guides the early intervention process for children with disabilities and their families. The IFSP is the vehicle through which effective early intervention is implemented in accordance with Part C of the Individuals with Disabilities Education Act (IDEA). It contains information about the services necessary to facilitate a child's development and enhance the family's capacity to facilitate the child's development. Through the IFSP process, family members and service providers work as a team to plan, implement, and evaluate services specific to the family's concerns, priorities, and available resources. (source) A service coordinator
then helps the family by coordinating the services outlined in the IFSP. Download the Model IFSP Form published by the U.S. Department of Education.

Writing the IFSP. From the Center for Parent Information and Resources (CPIR), the legacy resource for NICHCY.

The State Interagency Coordinating Council (SICC)

Each state has a State Interagency Coordinating Council (SICC). According to IDEA, the function of the ICC is to "advise and assist the lead agency in the performance of the responsibilities set forth in Section 635(a)(10) of the Individuals with Disabilities Education Act, particularly the identification of the sources of fiscal and other support for services for early intervention programs, assignment of financial responsibility to the appropriate agency, and the promotion of the interagency agreements; advise and assist the lead agency in the preparation of applications and amendments thereto; advise and assist the State educational agency regarding the transition of toddlers with disabilities to preschool and other appropriate services; and, prepare and submit to the Governor and to the Federal Secretary of Education on the status of early intervention programs for infants and toddlers with disabilities and their families operated within the State."

Transitioning out of Part C and into Part B (Special Education)

Your team (including parents) should start preparing the child for transition (if applicable) into Part B services around the age of 30-32 months (and no less than 3 months prior to the child's 3rd birthday). All children will not be eligible to enter into preschool special education programs. A transition planning meeting will be held to discuss next steps, particularly, how to prepare your child for the transition out of Part C. An exit IEP is held which determines the services that your child will receive after the transition. The following resources will help you understand this process:

Foundations of Transition for Young Children - Effective Transition Practices in Early Childhood.

Part C: The Transition Process and Lead Agency Notification. This Training Module 8 takes a detailed look at what the Part C regulations require in terms of the transition planning and activities that must occur from the Center for Parent Information and Resources (CPIR), the legacy resource for NICHCY.

Part C: Development of the Transition Plan. This Training Module 9 focuses on the development of a transition plan for the exiting toddler from the Center for Parent Information and Resources (CPIR), the legacy resource for NICHCY.

Transition to Preschool. From the Center for Parent Information and Resources (CPIR), the legacy resource for NICHCY (closing September 2014).

Transition of Young Children in Early Childhood Programs from CONNECT: The Center to Mobilize Early Childhood Knowledge from the Child Development Institute at UNC. This training module is about transition from Part C of IDEA (infants and toddlers - birth to three) to Part B (young children - three to six) programs.

Transitioning from Early Intervention. A booklet about leaving early intervention services at age 3 and transitioning to pre-school or other programs. Compiled by parents in New Jersey.

http://www.wrightslaw.com/phprint.php

10/10/2016
Early Transitions for Children and Families: Transitions from Infant/Toddler Services to Preschool Education. This ERIC Digest covers transition issues such as achieving successful transitions, what influences the process, strategies and processes.

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Articles

Parent Participation in Early Intervention. Resources from the legacy resource for NICHCY (closing September 2014) that address parent involvement, including the parents’ right to be involved in decision making regarding their child and the early intervention services he or she receives. There are also resources to help early intervention systems promote the active involvement of families at either the organizational or individual levels.

The "Low Down" on Service Coordination. According to 34 CFR 303.23 of IDEA, "the activities carried out by a service coordinator to assist and enable a child eligible under this part and the child's family to receive the rights, procedural safeguards, and services that are authorized to be provided under the State's early intervention program." This document from NECTAC is all about service coordination.

What's the Difference Between an IEP and an IFSP? PACER Fact Sheet with side-by-side comparison of an IEP and an IFSP.

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For cases related to special education, please visit the Law Library. More information on this topic coming soon.

Recommended Publications

Frameworks for Response to Intervention in Early Childhood developed by the Division of Early Childhood of the Council for Exceptional Children, the National Association for the Education of Young Children, and the National Head Start Association.

Transitioning to Kindergarten: A Toolkit for Early Childhood Educators. Too often, preparation for kindergarten does not begin until a month or two just before kindergarten begins. However, transition to kindergarten is a process that is most successful when it is carefully planned out over the entire pre-kindergarten year.

A Child Becomes A Reader: Birth Through Preschool. This free publication from the U.S Department of Education includes ideas about how parents can help their child become a reader when they talk, play, and read together. It is specifically written for parents with children of preschool age or younger.

Learn the Signs, Act Early. On this website, you can view or download the various materials for the "Learn the Signs, Act Early." Campaign designed for parents and health care professionals.

Early Intervention Process. This section on the Educational and Developmental Intervention Services (EDIS) from the U.S. Army Medical Department provides detailed information and resources associated with the eight steps in the early intervention process for military families.

http://www.wrightslaw.com/phprint.php

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Resources

New! Identifying Children who Need Early Intervention or Special Ed Services. The American Academy of Pediatrics Report, December 2015, highlighting the role pediatricians have in identifying children who need early intervention (EI) or special education services. Download PDF

Early Learning: Kindergarten Online Database. This database provides state policy information as of December 2012 on the 50 states and the District of Columbia, including: whether a Child Must Attend Kindergarten, Kindergarten Entrance Age, Compulsory School Age, Kindergarten Readiness Assessments, Curriculum, Minimum Required Days/Hours for Kindergarten, Kindergarten Standards - General Information and Teacher/Student Ratios.

Early Intervention for Children with Complex Communication Needs. This website provides guidelines for early intervention to maximize the language and communication development of young children with Autism Spectrum Disorders, Cerebral Palsy, Down Syndrome, and Multiple Disabilities. You'll find (1) Step-by-step guidelines for early intervention to build language and communication skills and (2) Photographs and videotaped examples of intervention with young children with special needs.

Recognition & Response: Evidence-based Practices. In recent years, the words evidence-based practice have become part of our everyday vocabulary in early childhood. The growing use of this phrase suggests that there are definitive answers to a host of complex practice-related issues. Most would agree in principle that early childhood professionals should rely on evidence to make important decisions about how services and supports should be provided to young children and their families. But what does evidence-based practice mean? How is evidence-based practice different from recommended practices? What precisely does it mean for the early childhood field?

National Center for Learning Disabilities Literacy Program: Get Ready to Read! Get Ready to Read! is an early literacy program designed to help parents, early educators and child care professionals ensure that young children are equipped with the fundamental skills necessary for learning to read. The goal of Get Ready to Read! is to screen four-year-olds for early literacy skills before they enter kindergarten and provide skill-strengthening activities to ensure reading success.

The Center for Best Practices in Early Childhood. Western Illinois University. This site provides information and resources on early intervention and special education practices.

NICHCY: Special Education Services for Preschoolers with Disabilities. From the Center for Parent Information and Resources (CPIR), the legacy resource for NICHCY (closing September 2014).

NICHCY compiles disability-related resources for each state, and creates State Resource Sheets. Each state-specific resource sheet will help you locate organizations and agencies within your state that address disability-related issues, including listings by state of the early intervention and special education program contacts.

Bridges4Kids Disability-specific Topic Pages. From Early Childhood Disorders to Learning Disabilities. Bridges4Kids provides topic pages on 85 different disorders, disabilities and diseases. Each page contains information on Education & Classroom Accommodations, National Resources & Websites, Articles, Medical Information, and more.
