

May 21, 2009

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Dear Lorene,

Thank you for this opportunity to provide testimony on the proposed revisions to He-M 510, Family-Centered Early Supports and Services. My name is Bonnie Dunham, and I am the parent of two children, one of whom received early supports and services (then called early intervention). The system that was in place at that time provided critical supports, services, rights and protections for my son and our family. Now that my children have grown into wonderful, productive and socially responsible adults, I feel an obligation to help ensure that infants and toddlers with disabilities and their parents are able to enjoy those same supports and services today and tomorrow. Therefore, I am very concerned about some of the changes being proposed to He-M 510.

I also work at the Parent Information Center (PIC), which is New Hampshire's Parent Training and Information Center on Special Education. Through my work at PIC, I am fortunate to be able to speak with many, many parents each year who depend on the State to provide their children with appropriate and necessary early supports and services, and later a free appropriate public education. All of the input that I have heard regarding these proposed rules echoes many of my concerns.

First, knowing how important it is that parents have the information they need to effectively advocate for their children, please consider reformatting He-M 510 (or making a reformatted version) that follows the layout in the *NH Rules for the Education of Children with Disabilities*, so that whenever Part C of IDEA or any other Federal or State law or regulation is referenced, the text of that referenced portion of the law or regulation is included below the reference, perhaps in a box to set it aside from the rest of the document. This format would allow the reader to fully access the regulation and better understand its intent without having to refer to other laws. One example of where this would be helpful is in proposed He-M 510.16, which says, "*An interagency coordinating council shall be established and operated pursuant to 34 CFR Part 303, Subpart G.*" Without having the Federal regulations in front of them, parents could not possibly understand the meaning of this section.

While I appreciate that it can be expensive to meet the needs of infants and toddlers with disabilities (and as a parent of such a child, believe me, I do appreciate it), it is critical that we not sacrifice the future of these children to save a few dollars now. The Individuals with Disabilities Education Improvement Act, Parts B and C, establishes a minimum standard that all states are required to meet, but it is intended to be a "floor", not a "ceiling". In some areas, I am concerned that NH seems to have slipped below the floor, into the basement, and in other areas seems very reluctant to do more than the minimum required by IDEA, even when we know that it will benefit children and families.

One of the purposes of IDEA, Part C is stated in Sec. 303.1. "**The purpose of this part is to provide financial assistance to States to – (c) Enhance the States' capacity to provide quality early intervention services and expand and improve existing early intervention services** being provided to infants and toddlers with disabilities and their families [emphasis added]". The intent clearly is that early supports and services provided by states be expanded and improved, not reduced and made less accessible to families.

I have listed below, in a format that I hope will be helpful to you, some specific recommendations, with references to the applicable sections of proposal for revising He-M 510:

Reference	Comments/Recommendations
Overall	This proposal seems to use the terms, “early intervention” and “early supports and services” interchangeably. I recommend using one term consistently with perhaps the other term being defined to clarify that it has the same meaning as the first term.
He-M 510	I would recommend adding at the beginning of the document in accordance with IDEA, Part C, Sec. 303.500, He-M 510 a statement identifying the lead agency and stating that the lead agency “is established or designated by the Governor; and is responsible for the administration of the system, in accordance with the requirements of this part.”
He-M 510.02(a)	I would recommend that the first time the term, “commissioner” is used, it say what the commissioner is the commissioner of; or that the term, “commissioner” be defined in these rules as it is in He-M 203. I also question the language change in this definition <i>from</i> people first language (“persons with developmental disabilities”) to “developmentally disabled persons”.
He-M 510.02(b)	IDEA, Part C, Sec. 303.322 combines “evaluation and assessment”, which seems much less complicated than He-M 510 defining “evaluation” and “assessment” separately, including some components of “evaluation and assessment” definition in each, but leaving out some pieces altogether. Restoring the language in what was He-M 510.02(j) the definition of “evaluation” would correct these omissions.
He-M 510.02(e)	In the definition of a “child with a developmental delay”, I disagree with the requirement of a 33% delay in one or more of the child’s developmental areas. Why “33%”? I would support revising this to say, “with a delay of 33% in one area or 25% in 2 or more of the following areas...”
He-M 510.02(h)	<p>While this section says, the parent has been fully informed in the parent’s native language or other mode of communication ...”, it does not define “native language”. This definition is required by IDEA, Part C.</p> <p>Also, I question why we use the term, “approval” instead of “consent” as is used in IDEA, Part C 303.401(a)(1)? Also, I recommend rewording this definition, as He-M 510.02(h)(1) & (2) refer to the future “for which approval is sought”, while (3) is written in the present “approved activity” (should be “activity for which approval is sought”).</p>
He-M 510.02(i)	This definition for “Family-centered early supports and services (FCESS) program” says that it “means a program under contract with the department to provide family-centered early supports and services as defined in these rules.” It would be helpful to define the term, “department” (a definition was included previously in He-M 510.02(i)). Also, this definition’s use of the phrase, “as defined in these rules”, is not accurate. They are “listed” (see He-M 510.03(a)(2) & (b)).
He-M 510.02(k)	I have serious concerns about the definition for “foster parent”, which establishes situations under which foster parents would have the authority to act as the child’s “parent” in the ESS system. IDEA, Part C 303.19(b) allows states to limit foster parents’ authority to automatically assume the role of the child’s “parent” and be able to make decisions for the child in the ESS system. In NH, for children with disabilities, ages 3-21, foster parents must meet criteria, including demonstrating knowledge and skills to make educational decisions on the child’s behalf. This is important so that children have already experienced some life circumstance that prevents them from living with their parent is not further disadvantaged by being represented by someone who lacks the knowledge or skills to perform effectively in that role. While a child’s “parent” may lack these skills or knowledge, they do have the advantage of having been involved with the child throughout the child’s life, so can bring that experience to their role as their child’s ESS decision-maker. Also, since the foster parent would be making decisions in the NH ESS process for an infant or toddler with disabilities, shouldn’t He-M 510.02 (k) reference He-M 510 instead of Part C?

He-M 510.02(n)	To the definition of "Individualized family support plan (IFSP)", which says, "means a written plan for providing supports and services to an eligible child and family", I would recommend adding the phrase, "that is developed in accordance with He-M 510.07" should be added to this definition.
He-M 510.02(q)	I recommend changing in the definition of LEA, the phrase, "school district responsible", to "school district that is or that will be responsible", changing "educational services" to "special education services", and changing "child" to "child with a disability" since LEAs are not responsible for providing services to children, ages 3-5 who do not have disabilities?
He-M 510.02(u)	This section, which lists the family only as <i>participants</i> in the evaluation process, is not consistent with 510.06(i), which says that the evaluation are " conducted by a team composed of the family, other persons requested by the family, and professionals from 2 or more different disciplines identified in He-M 510.12 (c)(1)" [emphasis added].
He-M 510.02(v)	In the definition of "natural setting", I recommend adding the phrase from IDEA, Part C Sec. 303.18, "the child's age peers".
He-M 510.02(w)	In the definition of "natural supports, I recommend replacing the term, "baby-sitters" with "child care providers".
He-M 510.02(x)	<p>The definition of "parent" uses the term, "ward of the state", a term that NH does not use. The <i>NH Rules for the Education of Children with Disabilities</i> instead says, "in the custody of DCYF".</p> <p>Also, I reiterate my recommendation that a foster parent should be required to demonstrate knowledge and skills (as is required in the <i>NH Rules for the Education of Children with Disabilities</i>, Ed 1115.06(c)) before assuming the role of the child's parent/ESS decision-maker. Having been an educational surrogate parent to 2 children, and conducted the training for surrogate parents under the <i>NH Rules for the Education of Children with Disabilities</i>, I know how important it is that the child be appropriately represented. This section also seems to refer to the wrong sections of the <i>NH Rules for the Education of Children with Disabilities</i> (which were recently revised). These references do not include the sections describing the training of educational surrogate parents, and refer to special education, not early supports and services. It also refers to the Commissioner of the NH DOE instead of the Commissioner of DHHS. Ed 1115.06(c) describes how foster parents can become surrogate parents. He-M 510.02(x) should use section Ed 1115 in the <i>NH Rules for the Education of Children with Disabilities</i> as a foundation for writing clear and comprehensive rules for surrogate parents to represent infants and toddlers with disabilities in the ESS process. Such rules would have to meet the requirements in 303.406:</p> <p>This definition also uses the term, "Personally identifiable" which should be defined. A definition is provided in Part C, Sec. 303.401(c).</p>
He-M 510.02(ab)	I support replacing "Team" with "IFSP Team", and adding from IDEA, Part C Sec. 303.343(a), "The parent or parents of the child"; "other family members, as requested by the parent, if feasible to do so" (instead of "family members"); "an advocate or person outside of the family, if the parent requests that the person participate"; the service coordinator who has been working with the family since the initial referral of the child for evaluation, or who has been designated by the public agency to be responsible for implementation of the IFSP; a person or persons directly involved in conducting the evaluations and assessments in Sec. 303.322" Also, add to (2) "who will be or who are providing services to the child or family". Add, "If the person or persons directly involved in conducting the evaluations and assessments in Sec. 303.322" "is unable to attend a meeting, arrangements must be made for the person's involvement through other means, including-- (i) Participating in a telephone conference call; (ii) Having a knowledgeable authorized representative attend the meeting; or (iii) Making pertinent records available at the meeting."
He-M 510.03	I recommend restoring "nursing services" and "nutrition services" in the list of early supports and service categories (they are still included in IDEA, Part C).

He-M 510.03	The following note from IDEA, Part C, which follows the list of early intervention services, should be included either at the beginning or end of He-M 510 – “Note: The lists of services in paragraph (d) and qualified personnel in paragraph (e) of this section are not exhaustive. Early intervention services may include such services as the provision of respite and other family support services.”
He-M 510.03(a)	In addition to defining, “assistive technology services”, I believe that it would be helpful if assistive technology device were defined (as in IDEA, Part C Sec. 303.12(d)(1).
He-M 510.03(g)	The definition of “health services” excludes services related to the implementation, maintenance, replacement, or optimization, e.g., mapping, of a medical device that is surgically implanted, including cochlear implants”. I would support reflecting the <i>NH Rules for the Education of Children with Disabilities</i> , which has elected to cite the IDEA statute instead of the regulations (which expand on the intent of the statute), and not take a position excluding the maintenance or optimization of a surgically-implanted medical device as a related service.
He-M 510.03(o)	I recommend adding to, “service coordination”, which is a combination of the parts of Sections 303.12(d)(11) and 303.23: “Service coordination includes case management and other assistance and services provided by a service coordinator to enable an eligible child and the child’s family to receive the rights, procedural safeguards, and services provided under Part C or IDEA and He-M 510. The case management activities for which the family’s service coordinator is responsible on an ongoing basis include: coordinating services within the agency and with other agencies; serving as the single point of contact to assist parents in obtaining needed services and assistance, including those listed in the IFSP; coordinating the provision of early supports and services and other services (such as medical services for other than diagnostic and evaluation purposes) that the child needs or is being provided; facilitating the timely delivery of available services; and continuously seeking the appropriate services and situations necessary to benefit the development of each child being served for the duration of the child’s eligibility.”
He-M 510.03(r)	I am concerned about the statement that “transportation services shall include reimbursing the family for the cost of travel...”. IDEA, Part C, sec. 303.12(d)(15) does not include the phrase, “reimbursing the family”. This phrase may be problematic, as it infers that a family would always have to pay for transportation and then be reimbursed (which may or may not be a complex process that results in significant delays in reimbursement). Some families may not have the ability to “up front” transportation costs. Also, couldn’t transportation include ESS arranging for, or providing, transportation directly for the family?
He-M 510.05(a)	This section does not include a timeframe for providing parents written prior notice, IDEA, Part C Sec. 303.403 says notice must be provided “a reasonable time” before proposing to initiate..., but in the <i>NH Rules for the Education of Children with Disabilities</i> , we establish a specific timeframe giving parents 14 calendar days to consider the proposal. It would make sense to use that same timeframe in the ESS system. He-M 510.05(a) has a misplaced comma and missing required text. It should read, “... before proposing or refusing to initiate or change the identification, evaluation or placement of the infant or toddler with a disability, or the provision of early supports and services to the child and/or the child’s family.”
He-M 510.05(d)	To language in this section saying, “The notice shall be written in language that is understandable to the general public and in the family’s native language, unless it is clearly not feasible to do so”, I believe that it is necessary to add from IDEA, Part C Sec. 303.403(c)(2), “If the native language or other mode of communication of the parent is not a written language, the public agency, or designated service provider, shall take steps to ensure that— (i) The notice is translated orally or by other means to the parent in the parent’s native language or other mode of communication; (ii) The parent understands the notice; and (iii) There is written evidence that the requirements of this paragraph have been met. (3) If a parent is deaf or blind, or has no written language, the mode of communication must be that normally used by the parent (such as sign language, braille, or oral communication).”

He-M 510.06(a)	This section now limits eligible for family-centered early supports and services, to those families who are able and willing to provide access to their child’s public or private health insurance and assume the personal financial liability of all of the co-pays, deductibles, etc. that go along with that consent. See further comments in the section of this testimony referring to He-M 510.15.
He-M 510.06(f)	The requirements from Sec. 303.404 Parent consent should be included here: “(a) Written parental consent must be obtained before-- (1) Conducting the initial evaluation and assessment of a child under Sec. 303.322; and (2) Initiating the provision of early intervention services (see Sec. 303.342(e)). (b) If consent is not given, the public agency shall make reasonable efforts to ensure that the parent-- (1) Is fully aware of the nature of the evaluation and assessment or the services that would be available; and (2) Understands that the child will not be able to receive the evaluation and assessment or services unless consent is given.”
He-M 510.06(i)	This section on the multidisciplinary evaluation should include the following additional evaluation requirements from IDEA, Part C, Sec. 303.323: The evaluation and assessment of children and families must utilize procedures to ensure, at a minimum that -- “(a) Tests and other evaluation materials and procedures are administered in the native language of the parents or other mode of communication, unless it is clearly not feasible to do so; (b) Any assessment and evaluation procedures and materials that are used are selected and administered so as not to be racially or culturally discriminatory; (c) No single procedure is used as the sole criterion for determining a child's eligibility”. When this section refers to the family assessment, should, but does not include some of the required components of Part C, 303.322(d): “(1) Family assessments under this part must be family-directed and designed to determine the resources, priorities, and concerns of the family and the identification of the supports and services necessary to enhance the family's capacity to meet the developmental needs of the child; (2) Any assessment that is conducted must be voluntary on the part of the family; (3) If an assessment of the family is carried out, the assessment must-- (i) Be conducted by personnel trained to utilize appropriate methods and procedures; (ii) Be based on information provided by the family through a personal interview; and (iii) Incorporate the family's description of its resources, priorities, and concerns related to enhancing the child's development.”
He-M 510.06(j)	This section says, “(j) A child’s medical and other records may be used to establish eligibility without conducting a multidisciplinary evaluation if those records contain information regarding the child’s level of functioning in the developmental areas identified in (i) (7) above.” This seems inadequate, as the evaluation for eligibility looks at more than just “the child’s level of functioning in the developmental areas identified in (i)(7) above”; it also looks at the child’s strengths and needs.
He-M 510.06(n)	This section, which providing for an extension of the evaluation timeline when “exceptional family circumstances” require such an extension should be changed to better reflect the language in IDEA, Part C Sec.303.322(e), which refers to “exceptional circumstances” and does not limit these to “exceptional family circumstances”. To this section, a #(4) needs to be added, which says, “Develop and implement an interim IFSP, to the extent appropriate and consistent with He-M 510.07(a).” Also, it makes sense to continue to have the family sign the document extending this timeline as verification that the family agrees that these exceptional circumstances warrant such an extension. This document should, to the extent feasible, include an anticipated timeframe for completing the evaluation. Otherwise there is no documentation that the family is aware and in agreement of extending this critical timeline. If a requirement for parental consent for extending the 45-day timeline is established, then deleted section He-M 510.06(f) should be restored.

He-M 510.07(e)(7)	I believe that it is in the best interests of families to add to the IFSP component, which currently says, “A summary of the documented medical services such as hospitalization, surgery, medication, and other supports that the child needs or is receiving through other sources but that are neither required nor funded under He-M 510”, language from IDEA, Part C, 303.344(e)(1)(ii) & (2), “and the funding sources to be used in paying for these services or the steps that will be taken to secure those services through public or private sources”. Having the service coordinator (someone who is familiar with available resources) help the family identify other resources to help pay for medical services not covered under early supports and services can be an invaluable support to a family that is struggling to meet the complex medical and developmental needs of an infant or toddler with a disability
He-M 510.08(c)	This section which provides for the review of the IFSP, should include the following language from IDEA, Part C Sec. 303.342(b)(2) , “The review may be carried out by a meeting or by another means that is acceptable to the parents and other participants”. I also recommend adding from IDEA, Part C, Sec. 303.342(d)(2) adds for IFSP meetings, “(2) Meeting arrangements must be made with, and written notice provided to, the family and other participants early enough before the meeting date to ensure that they will be able to attend.” In the <i>NH Rules for the Education of Children with Disabilities</i> , parents are given at least 10 days written notice before any IEP meeting (although parents may waive the 10-day notice). This notice is really an invitation to a meeting and not a written prior notice as described in He-M 510.05. To afford parents a real opportunity to participate in these meetings, perhaps there should be a section on notice requirements for IFSP meetings. The language that is proposed for deletion in what was He-M 510.07(d) should then be added to that section. “(d) A written notice for the meeting required by (c) above shall be provided to the parents at least 10 days before the meeting. The notice shall state the purpose of the meeting, actions to be considered, and reasons for the actions. A description of procedural safeguards shall be provided.” The 10-day notice for meetings is clear, respectful of families, and reasonable for both parents and providers.
He-M 510.10(b)	I recommend adding some language to this section regarding transition to make the process clearer to families. Including the following section from Part C, 303.344(h) would accomplish this: “(1) The IFSP must include the steps to be taken to support the transition of the child, in accordance with Sec. 303.148, to-- (i) Preschool services under Part B of the Act, to the extent that those services are appropriate; or (ii) Other services that may be available, if appropriate. (2) The steps required in paragraph (h)(1) of this section include-- (i) Discussions with, and training of, parents regarding future placements and other matters related to the child's transition; (ii) Procedures to prepare the child for changes in service delivery, including steps to help the child adjust to, and function in, a new setting; and (iii) With parental consent, the transmission of information about the child to the local educational agency, to ensure continuity of services, including evaluation and assessment information required in Sec. 303.322, and copies of IFSPs that have been developed and implemented in accordance with Secs. 303.340 through 303.346.” Also, from Part C, 303.148(b)(ii), “In the case of a child who may not be eligible for preschool services under Part B of the Act, with the approval of the family, make reasonable efforts to convene a conference among the lead agency, the family, and providers of other appropriate services for children who are not eligible for preschool services under Part B, to discuss the appropriate services that the child may receive”
He-M 510.12(c)	This section deletes from the list of service providers: “nutritionists” and “orientation and mobility specialists” (both of which are included in IDEA, Part C, Sec. 303.312(e)). I recommend restoring both of these provider categories to this list.

He-M 510.14	I do not believe that this section includes all of the required components in IDEA, Part C, Sec. 303.460.
He-M 510.15	<p>These proposed changes are the most significant, in that they could effectively prevent some families from obtaining early supports and services for their infant or toddler with a disability. Requiring families to give access to their child’s private insurance to pay for early supports and services, regardless of the cost of deductibles, co-pays, and the long-term impact of a child exhausting his/her lifetime benefits for certain services, will mean that some families will no longer be able to afford services for their children. The financial burden that these proposed changes impose on families will have a very real impact on our most vulnerable and precious citizens, infants and toddlers with disabilities. Given the research showing the benefits of early supports and services, this proposed change seems “penny wise and pound foolish”.</p> <p>Continuing to provide the federally-required services (child find, evaluation and assessment, development, review and evaluation of the individualized family support plan (IFSP), service coordination and procedural safeguards), is of little benefit if the child and his/her family cannot then receive the services in the IFSP.</p> <p>I also have grave concern that the language stating that beyond those services that are required under Part C of IDEA, “additional services will be provided to children and families based on the availability of funding”. This change could result in some services being unavailable to families without insurance that funds the services, and opens the door to the establishment of wait lists for early supports and services.</p> <p>He-M 510.15 also does not include all of the requirements in IDEA, Part C Sec. 303.520(b), which sets requirements regarding the imposition on families of fees for services. This section discusses “sliding scale fees”, a term which infers that the fee will be fair and dependent upon a family’s income and not on the type or quality of the family’s insurance coverage, the cost of the family’s co-pays, or the number and intensity of the services needed by the child. The funding scheme being proposed in NH has none of the “fairness qualities” one would generally expect in a “sliding scale fees”, but instead includes a significant disincentive for families to access services to meet all of their child’s developmental needs. Most troubling is the situation that would arise if a family that would be compelled to pay high co-pays for services has more than one child with a disability, or has a child with multiple needs. That family would find themselves in the unenviable position of having to make a “Sophie’s choice”. In our situation, the co-pays and deductibles for the services our son received would have cost our family more than \$700 per month (at a time when his health needs prevented both parents from working). We couldn’t possibly have afforded that sum. I wonder, would we have chosen to get speech and language services so that he could talk, physical therapy so that he could walk, or occupational and early education services so that he would be prepared to participate in preschool when he turned 3?</p> <p>While parents giving consent for the use of insurance will be informed they may incur a financial cost, He-M 510 should require that families be provided with details of those costs, including the actual amount of the costs to the family (which could be hundreds or thousands of dollars in deductibles, co-pays and/or loss of available services later in their child’s life.</p> <p>I would recommend including the language from IDEA, Part B, §300.154, regarding parental consent for access to public or private insurance.</p> <p>Nowhere in He-M 510 is the language from IDEA, Part C included, which says: “the inability of the parents of an eligible child to pay for services will not result in the denial of services to the child or the child’s family”. This language provides a critical protection for families.</p>

He-M 510.17	I have concerns with the changes proposed that would allow waivers of up to 5 years in duration of specific procedures in He-M 510, with the option of then requesting a renewal at the conclusion of the waiver period. Five years seems like a very long time to waive a procedure, unless it could be shown that it was necessary to support the child's developmental needs or the family's needs.
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I would like the opportunity to provide more comprehensive testimony on these proposed changes at a public hearing, but I only became aware of the magnitude of the changes being proposed and was then able to obtain a copy of the proposal to review 10 days ago. I have also heard from a number of other parents who were unable to attend this hearing, but who would like an opportunity to give input at a public hearing. I ask you to please consider conducting additional public hearings at times and locations that will allow parents and other interested persons an opportunity to participate.

Both IDEA, Part C Statute (2004) and its current regulations (1997) require more than the single public hearing that is planned for the proposed changes to He-M 510. Section 637(a)(8) of the statute says that the state's application for Part C shall contain, "(8) a description of State policies and procedures that ensure that, prior to the adoption by the State of any other policy or procedure necessary to meet the requirements of this part, there are *public hearings*, adequate notice of the hearings, and an opportunity for comment available to the general public, including individuals with disabilities and parents of infants and toddlers with disabilities" [emphasis added]. The Part C regulations establish requirements for public participation **when changes to State regulations are proposed**: Sec. 303.112. "Each State *shall hold public hearings in a sufficient number and at times and places that afford interested parties throughout the State a reasonable opportunity to participate*" [emphasis added]. A similar requirement is in effect when a state is proposing changes to its special education regulations. When revisions were proposed to the *NH Rules for the Education of Children with Disabilities*, the State Board of Education met this obligation by conducting public hearings in the morning, afternoon and evening, and in north, south & central New Hampshire, providing parents, educators, service providers and other interested parties sufficient opportunities to participate in a public hearing.

Again, thank you for this opportunity to provide input on the proposed revisions to He-M 510. Even though I disagree with significant parts of the proposal, I appreciate all of the time and effort the Bureau put into developing these proposed rules. If you have any questions, or I can provide any additional information, I would be happy to speak with you.

Sincerely,

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