

NIH News*

Scientists Identify Mouse Embryonic Stem Cell More Like Our Own

The National Institutes of Health (NIH) recently announced that scientists have discovered a new type of mouse embryonic stem cell that is the closest counterpart yet to human embryonic stem cells. The cells are expected to serve as an improved model for human embryonic stem cells in studies of regeneration, disease pathology and basic stem cell biology. To read more about this study and National Institute of Neurological Disorders and Stroke (NINDS)-related research on other topics, visit www.ninds.nih.gov/news_and_events/press_releases/index.htm.

NIH Awards Nearly \$5 Million to Fund Knockout Mouse Repository

Increased availability of genetically altered mice will aid studies of human diseases

The NIH announced it will provide \$4.8 million to establish and support a repository for its Knockout Mouse Project (KOMP). This award is the final component of a more than \$50 million trans-NIH initiative to increase the availability of genetically altered mice and related materials. The University of California, Davis and Children's Hospital Oakland Research Institute in Oakland, CA, will collaborate to preserve, protect, and make available about 8,500 types of knockout mice and related products available to the research community. For more details on this study, visit www.nih.gov/news/pr/jun2007/ncrr-26.htm; more information about KOMP resources is available at www.komp.org. To request information or products, researchers can call 1.888.KOMP.MICE or send an e-mail to service@komp.org.

NIH Web Sites of Interest

NIH Bulletin

<http://getinvolved.nih.gov/newsbulletins.asp>

NIH News in Health — *a monthly newsletter with practical health news and tips based on recent research*

<http://newsinhealth.nih.gov/>

NIH Roadmap

<http://nihroadmap.nih.gov/>

NIH Director Dr. Zerhouni's Web site

www.nih.gov/about/director/index.htm

Neuroscience Blueprint Web site

<http://neuroscienceblueprint.nih.gov/>

MedlinePlus Web site

<http://medlineplus.gov/>

Clinical trial information

<http://clinicaltrials.gov>

IDEA News

The Individuals with Disabilities Education Improvement Act (IDEA) 2004, signed by the president in 2004 and published in the Federal Register on Aug. 14, 2006, contains important changes our families with children in school need to know.

Many of our families and stakeholders provided public comment on the degenerative disorder language and congress-included report language in the reauthorization of IDEA bill to address these concerns. The result is shown on the following page as addressed in the Comment Section of the Regulations. Our efforts resulted in no change to the regulations but families should use the responses listed to ensure their individual education plan (IEP) team works to meet the unique needs of our children. As always, it is our responsibility as parents to educate the IEP team on the degenerative nature of MPS/ML. The Legislative Committee will continue to assist parents in finding resources for special education. We recognize the challenge our families face when services are denied due to a child's decline. Some of the IDEA 2004 changes should help make our students IEPs more meaningful.

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*This information was obtained from the NINDS newsletter.

Part II Department of Education
34 CFR Parts 300 and 301
Assistance to States for the Education of Children with Disabilities and
Preschool Grants for Children with Disabilities
Final Rule

46684 Federal Register / Vol. 71, No. 156 / Aug. 14, 2006 / Rules and Regulations

Consideration of Special Factors (§ 300.324(a)(2))

Comment: A few commenters requested that children with medical conditions that are degenerative be added to the list of special factors considered by the IEP team. The commenters stated that the IEP team should consider the need for children with degenerative conditions to maintain their present levels of functioning by including related therapeutic services prior to the loss of their abilities, such as occupational and physical therapy, and other services to address the child's needs in the areas of self-help, mobility, and communication. *Discussion:* Section 614(d)(3)(B) of the Act does not include consideration of children with degenerative conditions as a special factor. We decline to add it to the regulations because we believe that the regulations already address the commenters' concerns. As with any child with a disability, the child's IEP team, which includes the parent, determines the special education and related services that are needed in order for the child to receive free and appropriate education. For children with degenerative diseases, this may include related services such as physical and occupational therapy (or other services to address the child's needs in the areas of self-help, mobility, and communication) to help maintain the child's present levels of functioning for as long as possible in order for the child to benefit from special education. In addition, as part of an evaluation or reevaluation, § 300.305 requires the IEP team and other qualified professionals, as appropriate, to review existing evaluation data on the child to determine the child's needs, which may include evaluations and information from parents, as well as medical professionals who know the child and the child's specific medical condition.

S. Rpt. No. 108–185, p. 33, and H. Rpt. No. 108–77, p. 112, recognized the special situations of children with medical conditions that are degenerative (i.e., diseases that result in negative progression and cannot be fully corrected or fully stabilized). For children with degenerative diseases who are eligible for services under the Act, both reports state that special education and related services can be provided to help maintain the child's present levels of functioning for as long as possible in order for the child to fully benefit from special education services. The reports also state, "The IEP team can include related services designed to provide therapeutic services prior to loss of original abilities to extend current skills and throughout the child's enrollment in school. These services may include occupational and physical therapy, self-help, mobility, and communication, as appropriate."

Changes: None.

Major Changes in IDEA 2004 relevant to MPS and related diseases

To learn more about these and other changes go to www.ed.gov or www.nichy.org/idealist.htm.

- Re-evaluations for special education services may not occur more than once a year, unless the parent and the district agree otherwise. Re-evaluations must be conducted at least every three years.
- If a parent refuses special education and related services based on initial evaluation, the district may not file due process to force the parent to accept the services. The district is then not required to provide a free, appropriate public education. A parent may, at a later date, ask for their child to be evaluated for special education services.
- Consistent with No Child Left Behind, special education and related services must be based on peer-reviewed research.
- The definition of "present level of performance" has been changed to include "functional performance." The new definition is, "A statement of your child's present level of academic and functional performance which will tell how the disability affects your child's involvement in general curriculum." **Note: This is the most important change for our families and should eliminate some IEP team member's unfortunate use of the term "not educational" when establishing goals for our children.**

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- The IEP must contain a statement of annual goals, including both academic and functional goals.
- Short-term objectives are no longer mandated except for children with significant cognitive disabilities who are taking alternate assessments or if the IEP team agrees short-term objectives are needed.
- Progress reports must relate to the annual academic and functional goals but a statement about ability to reach the goals by year end is no longer required.
- Transition to adult life must begin by age 16 vs. age 14. This includes courses of study and transition planning services.
- IEP members (not the local education agency, which usually is the principal) may be excused from meeting with parent and district permission. Alternate methods of conducting meetings are now allowed with complete team approval. Changes can be made to an IEP without a meeting. Parents need to request a copy of a revised document. An annual IEP meeting is still required.
- Parent handbook and procedural safeguards will be distributed once a year vs. every meeting.
- The school district has 10 days to respond to a state-level parent-initiated complaint unless the district notifies the state that it is challenging the complaint. Then the state hearing office has five days to respond. Resolution session is now required before moving on to due process. The district cannot bring an attorney unless the parent brings one. If the judge rules the complaint was to harass the district, parents may be ordered to pay school district attorney's fees.
- The new law no longer requires if a discipline violation is a cause of the disability for manifestation determination or a direct result in the district's failure to implement an existing IEP.
- The right for a student with a disability to stay in current placement pending an appeal is no longer required.
- A new statement allows for case-by-case determination for change in placement due to discipline or code of conduct violations.
- School districts cannot require a child to take medication as a condition of attending school, receiving an evaluation or receiving services.

Parents should study their state Web sites to find out when the implementation of the federal regulations go into effect.

New Department of Education Web Site

The U.S. Department of Education launched a new Web site, <http://idea.ed.gov>, to aid families, educators and administrators looking for information on the IDEA 2004. This site was created to provide a "one-stop shop" for resources related to IDEA and its implementation of the regulations. It provides cross references to other important education laws such as No Child Left Behind and the Family Education Rights and Privacy act. The site includes questions and answers and many other resources.

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