

Summary – Extended School Year & Summer Camp Planning

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Annette provided three documents to review:

1. **IEP 1 - 8** is a fillable IEP form, developed for use in Massachusetts but very much tailored to the federal law so it's applicable to all states. This form is important to obtain extended services during the summer months.
2. **Summer Program Checklist** -- Mirroring the checklist for students going back to school presented last fall (<http://www.mitoaction.org/blog/back-school-tips>), Annette has developed a checklist that looks somewhat similar but has some changes for summer.
3. **A Parent's Guide to Special Education**, published by the Federation for Children with Special Needs in Massachusetts, provides an overview of the IEP process. This guide serves as a good resource for those new to the IEP process.

Why Consider Extended Year Services? (slide 2)

Studies have shown that most kids experience some regression during the summer. Regression simply means a loss of previously acquired skills. Children deserve every opportunity to maintain their skill levels and even continue to learn and grow during the summer months. Preventing significant regression in learning is an important guideline to use when developing a plan for extended year or summer services. Studies show that the average student losses at least a month's worth of learning. Although very individualized, students with special needs are at risk for more significant losses. Summer programming also allows a student to continue to progress toward their individual goals. The older the student becomes and the closer he/she is to transitioning to adult services, the more important continuation of progress to end goals becomes. Higher level skills that the older students are working to achieve are much more important to future independence than the skills that are learned in early grades. Summer programming, therefore, becomes even more vital as the student ages.

IEP Team (slide 3)

Summer programming is a decision to be discussed by the IEP team, including:

- Parents
- Students, under certain circumstances. In Massachusetts, as of age 14, and federally as of age 16, the student is encouraged to participate in decision-making. Each state may have a different rule about how old the student should be when included. The degree of student participation will depend on the degree of disability.
- General education teacher(s)
- Special education teacher(s)
- Ancillary services, including health services if important for the child
- Liaison to the school district
- Any other people who may be important: therapists, school counselors, psychologists, doctors, or someone from the medical team, etc.

Extended School Year (ESY) Decision Factors (slide 4)

In general, a professional evaluation is not required to obtain summer services, but may depend on the school district. Determining if the program is designed to eliminate the risk of regression versus continuing to make progress is key for many schools. A three-year evaluation is required for all students under federal law and those evaluations can address the issue of regression. Having an evaluation done outside of the school system can be helpful, particularly when determining if an extended year service plan is required. Decision factors include:

- Unique needs require extended services to make meaningful progress in school.
- Demonstrated regression in previous years, or likely to show regression.
- Difficulty or length of time required to relearn lost skills.
- Degree of impairment.
- Behaviors or physical needs that require consistency and structure, including PT, OT, and speech therapy.
- Typical rate of progress for the child.
- Available alternatives, including the home.

What ESY Services are NOT! (slide 5)

ESY is not the same as summer camp or summer school. Schools cannot refuse to offer ESY Services because summer services are not offered to all students or no internal program exists.

ESY differs from summer school and regular school:

- May include ancillary services, but not in the same frequency.
- May not include one-to-one aides, even if the aide has been provided during the regular school year.
- Nursing services and specialized transportation are typically offered in the same frequency as the regular school year.
- Parents may have to do more work to pull a summer program together, which may involve negotiating and cost sharing with the school district.
- Parents may be asked to cost-share for programs that are more camp-like, but includes therapies and tutoring.

Schedule Modification (slide 6, and also found on page 6 of IEP document) – An IEP needs to provide documentation that the child needs a longer school year to prevent a substantial loss of previously learned skills and/or substantial difficulty in relearning skills. An IEP is a contract with the school that carries due process rights, meaning if the school does not uphold the contract, the parents have the right to seek compensatory services to make up for services not given to the child. It is vital to keep the IEP detail-oriented so that the services needed are clear and become enforceable.

Before Deciding on a Summer Program (slide 7)

- Review, update, or create the child's Individual Healthcare Plan.
 - New medications
 - Loss or gain in skills
 - New diagnoses, etc.
- Tour the proposed program, or speak to the program director or other families.
 - Impediments to participation -- mobility obstacles, for example
 - Medicines and/or special foods that need refrigeration
 - Emergency procedures in place for emergencies such as fire
 - Extreme temperature consideration
- Other considerations: (slide 8)
 - Staffing needs – one-to-one, familiar vs. new staff, medical staff needs
 - Location -- inside vs. outside, air conditioning, distance from home
 - Transportation issues

Communication (slide 9) with both medical and teaching staff

- Progress in school this past year
 - Teacher notes
 - Medical changes, healthcare challenges
 - Behavioral issues
 - Strategies that worked well that should continue in the summer program
 - Keep in mind that summer programs are often more physically demanding
- Meet with program or camp nurse and director to avoid future conflicts. The more comfortable the staff is with the child's medical issues, the less conflict will arise during the summer. Make sure parents are accessible for questions and that the staff is also accessible.
 - How accessible is the nurse?
 - Private nurse or aide available?
 - Set up notebook, email, or other communication tool to enhance communication between home and the program.

When Conflict Arises -- Call a Team Meeting (slide 10)

- Reopen lines of communication for any issues that arise.
- If child is not safe in the summer program, pull the child from the program and then address the issues.
- Help others understand the complexity of planning for a child with Mito.
- Some districts may delay a meeting due to the lack of staff during summer hours, but nevertheless, key personnel would be available. Call for team meeting in May to hammer out the details of the summer program! Plan early.

- School districts want to avoid liability in the event of a medical crisis.
- Parents can lodge a complaint for services not rendered under the IEP, but may take time to resolve.
- Appeals tend to be useful for eligibility issues.

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In summary, much of the work of finding the best summer program falls to parents. The legwork in seeking out a program that meets the child's medical, social, and educational needs, however, can help that child have a positive and productive summer experience.