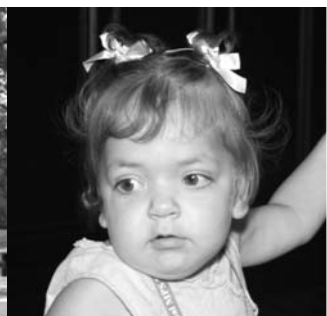




National  
MPS  
Society

Support for Families. Research for a Cure.



# Education Strategies and Resources A Guide for Parents

The National MPS Society exists to find cures for MPS and related diseases. We provide hope and support for affected individuals and their families through research, advocacy and awareness of these devastating diseases.

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## Introduction

While many parents of children with MPS and related diseases are satisfied with the education their child is receiving, a significant number of parents have difficulty getting an appropriate education for their children. This occurs despite the fact that most parents and



MATTHEW (MPS VII)

educators want the best for their children. So what gets in the way? Sometimes it is the way public schools are organized and operated. Sometimes it is a lack of knowledge on the part of parents or educators about MPS diseases. Sometimes parents and educators have a lack of confidence in working with children with serious disabilities. This booklet is designed to provide a source of information for parents and educators. It is not meant

to be an exhaustive resource, but attempts to pull together some information on strategies and resources that can be used to help devise an appropriate educational program for children with MPS diseases. There has been very little research on the behavioral and educational aspects of the MPS diseases. This booklet brings together the experiences of parents and educators who have developed successful education programs and useful techniques, and addresses difficulties commonly experienced by children with MPS. This booklet is dedicated to all of the hard-working parents and educators and, most of all, to our children. It is for them that we undertake this endeavor.

## How schools work

Understanding how schools are organized can decrease the frustration parents may experience. Much of the behavior of school personnel relates to how the school is organized and is not directly related to parents or children. Parents of MPS children must often ask school personnel to do something outside their norm. Give them time to adjust to your requests. See how you can support them as they adjust to the new expectations you are requesting. Compliment them on what they do well.

## Schools as organizations

All organizations have a particular way they operate; many are most comfortable following standard protocol. Schools have a division of labor based on specialization. Education is organized to meet the needs of the group, and education programs are conducted by regular or general education teachers. Special education was developed for those students who do not do well in general education classes. General education teachers have been told for years to refer to special education for children whose educational needs cannot be met in a general classroom.

Bureaucracy is another feature of schools. Bureaucracy refers to a chain of authority. The classroom teacher and others cannot make school operational changes without getting approval from their superiors. Change generally occurs from the top down, meaning that school policy changes usually result from directives from central office administrative staff. This limits how easily changes can occur in normal school operations, and teachers may not be free to independently make necessary and needed changes in educational programming. Difficulties developing an Individual Education Program (IEP) often result from problems with school policies or getting permission from superiors to make changes.

### A teacher's life

Teaching is a very complex activity. Most teachers want to do a good job. Many are getting fewer rewards than teachers used to receive. Teachers feel vulnerable and frequently feel blamed for problems within the education system. The community today is generally less supportive of teachers, and many teachers are under the pressure of having their students perform well on high-stakes testing mandated by the No Child Left Behind Act. The typical classroom teacher may feel that children who are different are threats to their performance. Many school systems do not reward teachers for working with students with disabilities.

### The role of parents

Parents frequently are in a position of asking teachers to do things that go against the norm of the school. Without approval from their supervisors, teachers may not be able to make changes that both parents and teachers are recommending. Teachers' superiors may not always be knowledgeable about special needs children. From

the beginning, it may seem like the system does not want to help children with special needs. It is important to remember that this usually isn't personal to the parent or to the child, but is a result of the way schools are organized. The job of parents is to understand and then help the school system plan for developing an IEP.

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## Laws affecting schooling for children with special needs

### An overview

There are three major laws that affect educational practice for children with disabilities. These are the Individuals with Disabilities Education Act (IDEA), Section 504 of the Vocational Rehabilitation Act of 1973, and No Child Left Behind (NCLB).

The IDEA sets the parameters for special education services for children with disabilities. All states must follow this law when providing services to children with disabilities. In addition, there are a number of regulations the United States Department of Education has developed to help implement this law. Schools also

The Individuals with Disabilities Education Act requires schools to provide free and appropriate education, at public expense, to all children with disabilities.

must follow these regulations. The IDEA laws were revised in 2004 and include a number of requirements for special educational programs. Some of these provisions include having an IEP team (with the parent as an equal member of the team), identification of the needs and goals for a specialized educational program, and development of an IEP

for each child who needs special education. The IDEA requires schools to provide free and appropriate education, at public expense, to all children with disabilities. This educational program is to be provided in the regular education classroom, with appropriate supports and services, unless absolutely impossible. Children with disabilities must have the most contact possible with children without disabilities. There are other specific steps schools must provide for students with disabilities. Parents should be familiar with the law and regulations.

The other law that applies to children with disabilities, Section 504 of the Vocational Rehabilitation Act of 1973, is a civil rights law. This law prevents schools from discriminating against children with disabilities by denying them access to schooling at the same level of children without disabilities. The definition of handicap is different from that of the IDEA, and children who may not qualify for special education services (for example, a child with the less severe form of MPS II) may still obtain an IEP through Section 504. Section 504 requires a committee of persons to meet to determine whether a child qualifies for a 504 plan and to develop the IEP. Children who qualify for a 504 plan can receive whatever services are necessary to have equal access to an education. This includes receiving special education services if necessary (even if they did not qualify for special education services through the IDEA).

See "Resources for More Help" at the end of this booklet for Web site addresses and books with information about Section 504 and the IDEA.

## Planning for educational programs and supports

### Educational needs: The big picture

Many school systems will have some initial difficulties when planning for children with MPS diseases because of their unfamiliarity with these diseases and lack of experience with children who have progressive diseases. Following are some of the "big picture" issues schools should consider when developing an IEP for a child with MPS. It is difficult to write specific guidance that covers every MPS disease, as there is such variation in characteristics between mild and more severe forms of the diseases. No child can be refused a free and appropriate public education, even those who are very impaired. There is no provision in the IDEA that requires a child progress and gain skills to be eligible for services.

No child can be refused a free and appropriate public education, even those who are very impaired.

### Early intervention

Infants and very young children with MPS diseases may obtain substantial benefit from an early intervention and stimulation

6 program where maximum intellectual gain can be encouraged. This is especially important in those diseases in which early plateaus in learning occur. Enrolling a child in a preschool early intervention program as soon as the diagnosis is made is warranted. All localities have early infant stimulation programs, however each state will likely operate the program from a variety of agencies, such as the school system, mental health and mental retardation services, or public health department. The school system can recommend to parents the appropriate agency to contact.

### Overall planning and monitoring considerations

Because of the rapid regression in skills and behavior experienced in the severe forms of MPS, schools should frequently monitor changes in behavior so the IEP can quickly be adapted as needed to support a child who is losing skills. The IEP should be developed to encourage social and academic participation, new learning and



CAROL (MPS IV)

the preservation of established skills. Alterations to the learning environment and methods of instruction are frequently necessary to adapt to difficulties with cognitive skills, mobility or behavior problems. Teachers frequently need additional support to accept the limitations of the child's skills and disease progression, and to resist the impulse to demand performance for which the child is not capable. Planning and goal development

may be difficult for school personnel who do not have experience with children whose diseases are progressive. The traditional focus is on improvement of skills and lessened support as improvement occurs rather than maintaining skills. The IDEA 2004 includes commentary which supports services for the "maintenance of function" rather than for obtaining new skills.

### Medical care needs

Mobility problems, hearing loss and vision difficulties may need the special attention of school personnel in program planning. All schools should have teachers who specialize in working with children with vision or hearing impairments. These teachers help the IEP team develop alterations to deal with these problems. Mobility problems and limitations due to physical manifestations of the

7 diseases can be addressed by consultation with physical and occupational therapists and adaptive physical educators. Class assignments and projects (such as art projects) can be modified to allow children with physical limitations to participate in similar projects with their peers.

### Behavior problems

Behavior problems may be identified by school personnel as misbehavior rather than symptoms of MPS diseases. For children with typical, more severely handicapping forms of MPS, most behavior problems are likely caused by neurological issues, lack of understanding, difficulty with communication or sensory limitations.

School personnel must take an intervention approach to these problems rather than a discipline approach. Sending the child to the principal's office is not the most appropriate way to deal with behaviors that are a result of a medical condition. Behavior difficulties should be treated as a complication of the medical condition and not as misbehavior. Alterations to the learning environment and methods of instruction may be helpful in decreasing some behavior problems. Teachers and administrators may need training and consultation in interventions for over-activity, restlessness and fearfulness. Behavior support and management principles should be well known by teachers and school psychologists. There should be an emphasis on modification to the classroom environment and the use of reinforcements to promote appropriate behavior.

For children with typical, more severely handicapping forms of MPS, most behavior problems are likely caused by neurological issues, lack of understanding, difficulty with communication or sensory limitations.

### Socialization

School attendance and socialization should be encouraged and fostered through classroom integration and specific social skills interventions. Independence should be supported. Teachers can do much to improve the acceptance of the child through instructional activities, such as cooperative learning and encouraging support for all children in the classroom. Additional support and education is necessary during adolescence, especially for adolescents with mild MPS I and II, MPS IV and MPS VI.

## 8 Teacher education and support

Teachers should be educated about the child's disease, abilities and special needs. Teachers may be unsure of their ability to teach children with these diseases, but many skills they use in teaching non-disabled students will enable them to work well with children with MPS. Teachers should have access to personnel with more expertise, such as school psychologists or behavior specialists, when needed. Teachers also may need support in dealing with feelings of loss if the child's condition worsens.

### Academic and career expectations

Teachers need appropriate expectations for learning that are balanced by an awareness of the child's limitations. Children with mild MPS I and II, MPS IV and MPS VI are likely to have normal or only mildly delayed intellectual development. Teachers should not assume there is significant retardation of intellectual development due to the outward skeletal manifestations of the diseases. Appropriately high expectations of academic achievement will foster realistic self-appraisal and enhanced academic achievement. Academic and vocational programming should foster independence

Children with mild MPS I and II, MPS IV and MPS VI are likely to have normal or only mildly delayed intellectual development.

and autonomy, and career goals should be set realistically high. Planning for transition from school to post-secondary education or work should focus on helping students pursue vocations in a manner that is similar to that of their peers.

## Placement issues

One of the most vexing issues in devising an educational plan for children is deciding where special education services will actually be delivered. The student's placement must be in the "least restrictive environment," the setting in which the student has the most contact possible with children without disabilities. Therefore, the IDEA requires schools to first consider educating children in the regular classroom with supplemental aids and services to meet their needs. It should first be determined what supplementary aids and services would enable the child to be educated in the regular classroom. When deciding on the least restrictive environment, the team should consider the following factors:

- the educational benefit to the child
- the non-academic benefit to the child (for example, social benefits)
- the potential harmful effects of a setting (such as lack of stimulation)

The impact of a child with a disability on other students also must be evaluated. A child with disabilities may disrupt the education of other students in the classroom. The IEP team must consider other placement if it is determined the child's needs cannot be met in the regular classroom, even with supplemental aids and services.

Schools are required to have a variety of placements available, ranging from services in the general education classroom, to part-time services in a resource room, to services in self-contained classrooms or special schools. Many parents want their child in the regular classroom and it becomes the IEP team's responsibility to prove that this cannot be done with appropriate supports and aids. Many schools want to serve children in self-contained classrooms along with other children with more serious disabilities.

A student's placement must be in the "least restrictive environment," the setting in which the student has the most contact possible with children without disabilities.

Special education law does not require that a student have the best placement, but only one in which they can obtain educational benefit. The best way to avoid placement problems is for parents to develop a list of the child's strengths, needs and goals.

### Inclusion

Inclusion is the practice of serving students with a full range of abilities and disabilities in the general education classroom with appropriate in-class support. Sometimes it is difficult to tell what people mean by inclusion. Some use inclusion to mean inclusion in regular education programs for four of six periods with instruction adapted only in two of the child's special education classes. Others have abolished all separate classes for special education and provide supportive services to all children in regular classes. As far as academic progress goes, inclusion seems to work for some students. Socially, there is no data to support whether inclusion is effective or not, and few studies have been conducted with children with



multiple disabilities. In theory, all required services could be provided in a regular education classroom. In practice, it seems that despite well-trained and equipped teachers and classrooms, not every child will benefit from inclusion practices.

Federal law does not mandate that local school districts provide full inclusion programs. However, a major principle of the IDEA is to



OWEN (MPS II)

provide services in the least restrictive environment that is similar to a general education classroom. Later court decisions have upheld that placement decisions begin with the assumption that the child can be educated in the general education classroom, and only when the child's education cannot be achieved satisfactorily with supplemental aids and services may the school consider placing the child

outside the regular classroom. Therefore, it is up to the school district to prove that the child cannot be educated in the regular classroom with special services and aids.

There are several parts of the IDEA that can be helpful to a parent who wants to advocate for a full inclusion program:

- Section 300.114 states that schools must include procedures to ensure that to the maximum extent practicable, the local school provide special services to enable children with disabilities to participate in regular educational programs.
- Section 300.116 states that IEPs must include a statement of the extent to which the child will be able to participate in regular educational programs.

When deciding on goals and placements for children with disabilities, schools are required to consider the academic and social needs of students and where these needs can reasonably be met. At times, this may result in the school wanting to include the child in an inclusion program even though the parent may wonder if this is the best placement. If this is the case, have the school document these needs and how inclusion specifically meets the child's needs. Monitor the child's outcomes in terms of academics: Are they making academic progress? Are they meeting their academic goals? For non-academic areas: Are they making social/emotional progress? Do they have friends? Do they enjoy school? Do they feel safe? Do they feel they have enough boundaries?

If the answer to these questions is yes, inclusion may be a good option. If not, and the parents don't like a placement option recommended by other team members, have the team document how they will deal with these concerns. Remember, parents have a right to mediation and appeal.

## Socialization

In determining the proper placement, parents should make sure the child's socialization aspects are not ignored by performing the following activities:

- Ensure the IEP team understands that all children benefit from social interaction at some level.
- Decide on overall socialization needs and goals for the child. Remember that for some children, increasing the number of friends and playmates is the goal, while for others it may be reducing interaction to a tolerable level.
- Form a social network in an inclusive setting. Meet with small groups of non-disabled students and have them develop a list of ideas on how to involve the disabled student in the school. Students who volunteer to get involved with these activities can form a peer network. Although the peers will first consider themselves to be advocates, this role may evolve into a friendship between the disabled and non-disabled students (Ford & Davern, 1989).
- Match your child with another child according to their preference for certain activities that improve the interaction between your child and others. These activities may take place in the school cafeteria, library, computer lab or gym.

## Behavior problems and placement

Some parents whose children have disruptive or challenging behavior have been told their child must be placed in a special class because the behavior is too disruptive to other students. Special education regulations do allow the consideration of whether a child's behavior is so disruptive that the education of other students is significantly impaired. In such a case, the school can implement a placement in a special education class, however, the education of the other children must be "significantly impaired" and "all reasonable steps" must first be taken to minimize the burden on the teacher and other students. Reasonable steps include a variety

12 of services to assist the child and the teacher, including an individual aide for the child. If behavior is a problem, have the school system document what has been done to assess and intervene the difficult behavior.

## Funding and placement

The cost of services is often a factor relating to placement. Some families have had the school principal tell the IEP team the child couldn't be placed in the regular classroom because there was no money budgeted for additional special education staff. The local school district cannot consider cost when determining what special education services your child needs. The IDEA mandates that there must be qualified personnel available and that the local school districts' budget cannot be a factor. However, courts have ruled that if two or more appropriate placements are available for a child, the IEP team members may consider cost to the school when determining a child's educational placement. Try to keep negotiating with the team members. Note why an inclusive placement is better.

The local school district cannot consider cost when determining what special education services your child needs.

# The Individualized Education Plan

## IEP goal setting

The first step in creating an IEP is to develop some broad goals for the child. While broad goals will vary from child to child, here are some examples:

- develop relationships with adults and children in school
- achieve as much self-help skill as possible
- be as self-directed as possible
- be happy with himself/herself and his/her school
- develop the desire to be independent
- utilize acceptable behavior at school
- be accepted by others, both students and adults

The next step is to look at the child's current performance and needs in a variety of educational areas, including:

- **ACADEMIC/COGNITIVE SKILLS:** Appropriate academic learning goals such as reading, math, social studies, etc. will vary according to the child's level of academic skill and potential. These goals also can include completing relevant tasks, becoming aware of the environment, etc.
- **EMOTIONAL DEVELOPMENT:** Developing satisfaction with school and life, satisfaction with self, improvement of self-control and enhancing personal efficacy.
- **SOCIAL DEVELOPMENT:** Developing friendships, interaction with peers, feeling part of a group, contributing to the good of the school and classroom, and having models of appropriate social behavior.
- **COMMUNICATION SKILLS:** Skills that develop understanding and communication with others. Improving and maintaining language skills, learning compensatory communication skills, and being exposed to and practicing appropriate language skills are examples.
- **SENSORY SKILLS:** Improving the effects of vision and hearing loss, providing a satisfactory and stimulating environment, and protecting the child from an environment that is too stimulating.
- **MOBILITY/PHYSICAL DEVELOPMENT:** Maintaining and improving mobility, coordination and physical skills. This includes regular and adaptive physical education activities and activities with other children.
- **MEDICAL/HEALTH NEEDS:** Supports that meet the medical and health needs of the child to enable him/her to benefit from his/her educational program.

## Strength-based planning—The child

Professionals are frequently trained to identify problems, and therefore tend to be on the lookout for difficulties rather than what is going well for children. Many people don't consider the fact that children with serious disabilities have strengths. Starting IEP planning with the child's strengths and likes can help change the tone of IEP meetings. It provides a new focus on the child that



14 can be built into the IEP program. Strengths and likes can be used as learning tools. For example, if the child likes animals, animal shapes can be used to teach addition and can be used as reinforcements for appropriate behavior. Animal stories can be read when the child is attentive. The focus on strengths and likes enhances motivation and allows everyone to enjoy the experience.

Children with serious disabilities have strengths. Strengths and likes can be used as learning tools.

Parents should ask the IEP team to focus on the child's strengths and likes. The team can refer to these strengths and likes when composing the IEP. Below are questions to ask about the child. Be open to new ideas as the meeting progresses.

- What is the child's favorite thing to do?
- What areas have had the most improvement?
- What has the child most improved on from earlier in the year?
- Who does the child like best in school (teachers, peers, other school staff)?
- What was the best day the child had this year? What activities and events occurred that day?
- What activities do the parent and child enjoy doing together?
- What does the child do well?
- What are the child's strongest physical and motor skills?
- If the child could do anything, what would it be?
- What are the child's favorite foods?

There are many more examples of questions parents can ask to help the IEP team identify the child's strengths and likes. Encourage other team members to brainstorm and think about specific times and events in the past few months that remind them of strengths and likes. Don't be discouraged if people have a difficult time doing this at first—it really is a different way of thinking and may take some practice.

## Strength-based planning—The school

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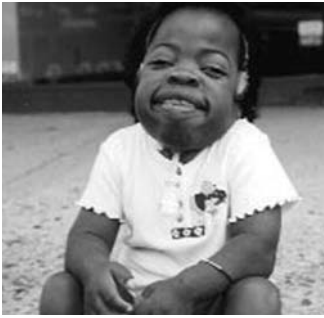
This approach also can be used when planning the classroom setting. Some professionals who work with children often refer to the “wraparound” approach to developing plans. The idea is to think in terms of what supports the teacher needs to help this student be successful. Parents can do a strengths and likes assessment of the teacher and classroom, too! Here are some ideas to get started on a school strength assessment:

- What are the best aspects of the classroom?
- What does the teacher do for fun in the classroom?
- With what types of children with special needs is the school most successful?
- What are some things children enjoy doing in the classroom?
- What aspects of teaching does the teacher do best?
- What types of students respond well to the teacher?
- What is most exciting for the teacher on the first day of school each year?
- Who are the most supportive individuals in the school?
- What are the teacher's favorite subject areas?

This also can be an illuminating process for the teacher. It gets people thinking about how to use their strengths to educate children. It may identify things that people haven't thought of in a long time. It also gets people to think about developing supports to better do their job and serve the children. It helps if parents have a few strengths of the teacher and school that have been identified before the IEP meeting.

## Preparing for the IEP meeting

Be an advocate for your child. Prepare ahead of time for the IEP meeting and keep the focus on what your child's needs and goals are. Review the child's records. Read over the last IEP. Make notes on areas where the child has improved and areas where there needs to be more work. Review any classroom work or progress notes received since the last review. Review reports or evaluations from outside professionals. Bring these reports to the meeting.



KARIMA (MPS VI)

Make a list of the child's strengths and a list of his/her needs. Think of academic, social, emotional and physical strengths. Involve the child and other family members. Make a list of the things that need to be done to meet the child's needs. Think in terms of classroom size, peers, accommodations, curriculum, modifications, related services, assistive technologies and transition. Make a list of the main points to be discussed at the meeting. Be sure to specifically discuss assistive technologies and adaptive physical education (discussed in later sections of this booklet). Read materials on IEPs and work with the school so you are prepared. A resource for materials is [www.wrightslaw.com](http://www.wrightslaw.com).

Parents may want another person to attend the meeting for support or to have another professional attend who can better explain the child's needs.

### Having a successful IEP meeting

- Don't forget to bring all the information to the meeting.
- Don't be intimidated by all the people. The parent is a full member of the team.
- If something is difficult to understand, ask to have it explained. Ask questions.
- Keep emotions in check. It may be difficult, but it is best to remain calm. It is helpful to have another person present to provide support. If the meeting seems to be too emotional, ask for a break or reschedule another meeting.
- Listen to what others have to say and agree with what is reasonable.
- Make sure all of what is decided is written down on the IEP and get a copy.
- If you disagree with the school, attach a written statement of the disagreement to the IEP and don't forget your right to appeal.

## Managing disagreement with the IEP

If the parent and school personnel don't agree on the IEP, focus on areas of agreement and work from there. Try to agree on as much of the IEP as possible so the school can begin implementing the plan.

Look for others to help (other parents, special education law centers, advocates for the disabled and organizations for children with disabilities). Take someone else with you to meetings who can observe and assist you.

Work hard at keeping cool during meetings. Write down goals and plans before going to meetings and provide evidence that backs the claims.

The IDEA provides for voluntary mediation to help resolve disputes between parents and schools over special services for a child. Previously, disputes were required to be settled by a hearing officer, which often led to legal expenses for both the parent and the school system. Money spent by the school district on legal expenses is money that doesn't go to special services. Mediation is a less adversarial process and may lead to increased cooperation between parent and school. One school district reports that 75 percent of lawsuits by parents are won by the school district. If that is the case, and parents can resolve disputes without going to a hearing, they are more likely to come to a satisfactory solution without the expense of time, worry and money.

If parents cannot come to agreement with mediation, they have a right to request a due process hearing by an impartial hearing officer who is not an employee of the school district.

If parents cannot come to agreement with mediation, they have a right to request a due process hearing by an impartial hearing officer who is not an employee of the school district. The local school district must inform parents of any free or low-cost legal services available, and that parents may be eligible to have their legal expenses paid for by the school district if they win their appeal. A hearing must be held and a decision reached within 45 days of their request for a hearing. If the parents are not satisfied with the results of the hearing, they may appeal to the state Department of Education for an impartial review of the decision. They also may follow this with civil court action if they believe the

18 school is not following the provisions of the IDEA. While the due process appeals are underway, the child would stay in the current placement unless the parents and the school agree on another placement during this time.

If the experience is difficult, hang in there. Remember, most of the time the local school district has the burden of proof that its programs are meeting the child's needs.

### **Monitoring progress with the IEP**

It is important to monitor the progress of your child's education by performing the following activities:

- Keep in touch with the child's teachers, principal and other related personnel. Visit the school as often as possible.
- Make sure the IEP is being followed.
- Keep a record of the child's progress of the IEP goals.
- Ask for a review of the IEP as the child's needs change.
- Make sure school personnel provide documentation that goals have been met or needs have changed.

Consider the following areas:

#### **ACADEMIC ACHIEVEMENT**

- Is the child making academic progress?
- Is he/she meeting the goals of the IEP?
- Does the teacher believe that academic goals are important for the child?
- Does the teacher encourage the child's best performance?
- Does the child have appropriate expectations of his/her academic performance?
- Does he/she try hard to reach the goals?

#### **SOCIAL DEVELOPMENT**

- Does the child have a variety of friends in the class (a close friend, some acquaintances)? How many friends and how often the child plays with them may be related to the child's basic temperament and ability level.

- Does the teacher promote social interaction between all students in the classroom?
- Does the child get to work cooperatively with other students during learning activities?
- Does the child participate in nonacademic activities (sports, socials, etc.)?

#### **EMOTIONAL DEVELOPMENT**

- Does the child like school? Is this a change?
- Does the child feel that he/she can master his/her environment at school?
- Does the child have strong negative feelings at school (anger, sadness, anxiety)?
- Does the child manage his/her feelings satisfactorily at school (anger, sadness, etc.)?

#### **SCHOOL ENVIRONMENT**

- Is the child getting an appropriate amount of assistance or support to reach his/her emotional, social and academic goals?
- Does the teacher understand the child's needs?
- Does the teacher want to teach exceptional children in the classroom?
- Are the classroom and other areas easily accessible for the child?
- Are appropriate modifications made to simplify the environment?
- Are school-related tasks modified where appropriate but still similar to tasks other children do?

#### **BEHAVIOR INTERVENTION PLANS**

All children who receive special education services and have behaviors that impede their learning or the learning of other children must have a behavior intervention plan as part of their IEP. This should include an analysis of the problem behaviors, along with an assessment of the factors that might cause these

behaviors. The program also should specify strategies to help reduce the problem behavior. These strategies should include

positive behavioral interventions, such as reinforcement (reward) for appropriate behavior, and teaching the skills necessary to perform the appropriate behavior.

There also should be attention directed to arranging the classroom environment to reduce stress on the child and to provide support for appropriate behavior.

An example of a situation where a classroom support is needed would be for a child who cannot communicate

his/her needs clearly and has anger outbursts as a result. One possible solution would be to provide a communication board with words or pictures that the child can point to as a way of communicating with the teacher or other children. If the communication need is met, there is less need for the child to become angry.

If a child's behavior problems interfere with learning, parents should make sure the IEP includes psychological services. This would allow the school psychologist to consult with the teacher in implementing behavioral interventions.

## Suspension from school

Suspension from school for behavior problems should be a rare occasion for a child with an MPS disease. Children receiving special education services may not have their educational placement

changed without an IEP team meeting and the change recommended in their IEP. Schools can suspend a child for up to 10 days before it is considered a change of educational placement. However, if a child is repeatedly suspended for less than 10 days, it may be considered a cumulative change of placement. In

that case, an IEP meeting must be held to discuss the child's IEP, including developing a behavioral intervention plan or reviewing and modifying an existing plan to improve the child's behavior. If a child is to be suspended or moved to an alternate educational setting for 10 or more days, then it is a change of placement.

The IEP team must then conduct a manifest determination to



KEVIN (MPS III)

Suspension from school for behavior problems should be a rare occasion for a child with an MPS disease.

establish whether the problem behavior is directly related to the child's disability. If so, the child may not be suspended for more than 10 days. The IEP team must review the child's placement and services and develop more effective ways to help the child. If the behavior is considered to be unrelated to the handicapping condition, the child can be suspended for more than 10 days since this would be the same penalty that non-handicapped students would receive if they engaged in the same behavior. The IEP team must then meet within 10 days to plan for a functional behavior analysis, which is an individualized analysis of the problem behavior. This should include the revision or development of a behavior intervention plan, as well as looking at the suitability of the classroom and the supports provided to the child.

## Dealing with difficult behavior

When dealing with difficult behavior, look closely at the environment and use consistent strategies to manage the behavior. Try to identify what the function of the behavior is. Sometimes there is no apparent reason for difficult behavior. Often behavior has a function, such as:

- to communicate anger, boredom, pain, hunger;
- to avoid a task the child finds unpleasant;
- to get something the child wants; or
- to discharge pent-up energy.

Look closely at the environment. Environmental change can often make a difference.

**SIMPLIFY THE ENVIRONMENT.** Frequent negative behavior results from an environment that is too complex, difficult to understand or has too high expectations. In these cases, try to simplify the environmental demands on the child.

**MAKE THE ENVIRONMENT MORE ATTRACTIVE OR STIMULATING.** Other times difficult behavior is the result of an environment that is boring or unattractive. Improving appropriate room decorations, activities and levels of stimulation can improve the learning environment.

**USE POSITIVE INTERVENTIONS FIRST.** Identify positive behavior and reinforce it as much as possible. Try to arrange it so the child is able to be successful at things and has more positive

interactions with people than negative interactions. Attention, praise, smiles and food are all examples of positive reinforcements.

**USE MILD PENALTIES.** Don't over punish negative behavior. Usually mild penalties will result in behavior changes. Removing the child from the situation, taking away a privilege and turning your back are all examples of mild penalties.

**DON'T TAKE IT PERSONALLY.** Much of the behavior of children with MPS diseases is not directed personally at caregivers. Taking it personally makes you angry and liable to become more punitive.

**BE CONSISTENT.** Consistency is often reassuring for children, especially those who have limitations in understanding or communication. Changing what one is willing to tolerate can make difficult behavior less likely to resolve itself. Consistently reinforce positive behavior and penalize negative behavior.

**FIND PEOPLE TO HELP.** School psychologists and special education teachers with experience in working with autistic children or children with emotional problems often are the best people to consult about behavior management.

Consider what others have done to assist with these specific behaviors.

- **FEARS**

- Consult/train teachers to intervene empathically.
- Behavior management and use of medication.

- **OVER-ACTIVITY/RESTLESSNESS**

- Provide a quiet place with little stimulation and few choices until calmer.
- Designate an activity table to include favorite books or toys for a one- to five-minute break.
- Take a walk around school, then go back and continue the activity.

- **AGGRESSIVE/DESTRUCTIVE**

- Physically protect and block the child. Put your hand on top of the child's hand to tell him/her to "stop" or "let go."

- Role model how to deal with anger.
- Label appropriate touching (i.e. no hitting) and use positive reinforcement of appropriate behavior.
- Teach other children to remind the child to use nice touching.
- Have other children leave a space around the child so he/she doesn't feel crowded.
- Teach others to approach the child from the front so as not to startle him/her.
- Arrange the environment to reduce frustration.

- **SENSORY STIMULATION**

- Assess undesirable behaviors that may be adopted because a person is trying to manipulate the environment to increase or decrease stimulation to a desired level. The function of sensory stimulation/automatic reinforcement is to increase or reduce stimulation.
- Check for possible health problems (such as ear infection) that may be uncomfortable.
- Provide an enriched environment (such as stimuli that match the behavior. For example, provide textured items to replace behavior that seems to provide tactile stimulation).
- Reduce sensory stimulation when over stimulation may be causing the negative behavior. Move to a quieter area, pad the area if necessary to prevent tactile stimulation.
- Change noise, crowding and room temperature to provide a more optimal environment based on the student's preferences.
- Consult with an occupational therapist for additional strategies.

*Approaches to Specific Behavior Problems (Dunlap, Ferro, Deperczel, 1994)*



## Adaptive physical education

MPS children, like all children, must have a physical education program. Public Law 101\_476 Section 1401 [16] (IDEA) makes physical education a required special education service. Section 504 of the Rehabilitation Act of 1973 (PL 93\_112) also provides that children cannot be deprived of activities that others engage in simply because they have a disability. The IEP should include the services



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of an adaptive physical educator. Adaptive physical educators learn how to adapt existing physical education activities and develop innovative activities to meet the physical, motor, personal, social and learning needs of children with disabilities.

The adaptive physical education teacher should assess the child's physical education needs and develop an adaptive physical education program as part of the child's IEP. Adaptations can be made in existing games to include children with disabilities. Some possibilities include using a batting tee instead of pitching in a softball game; having designated runners; decreasing the distances in games; using real teams where children assist each other in parts of activities; allowing children in wheelchairs to hold the ball on their lap while being pushed by another child; changing rules of games; modifying equipment; adapting the layout of the game space; and developing new games that stress interaction rather than competition.

Adaptive physical educators may work directly with children with disabilities and/or may provide consultation to teachers and parents

Every school district should have at least one adaptive physical educator.

on how to provide physical education activities that meet a specific child's needs. Every school district should have at least one adaptive physical educator. If not, one can be hired as a consultant. Evaluate the effectiveness of the goals and activities at

each IEP update, and have the adaptive physical educator present at the IEP meeting.

Parents can ask for an IEP team meeting if they aren't sure how things are going or if they aren't happy with the current status of their child's physical education plan.

## Assistive technology

The newest revision of the IDEA added the responsibility for IEP teams to consider whether a child needs assistive technology devices and services to accomplish the educational goals in the IEP. An assistive technology device is a piece of equipment or system used to increase, maintain or improve the functional capabilities of a child with a disability. These devices can be homemade or commercially available. Some devices may be specifically designed for persons with a disability, others may be commonly available.

An assistive technology device is a piece of equipment or system used to increase, maintain or improve the functional capabilities of a child with a disability.

Assistive technology helps compensate for limitations in functional skills caused by a disability. These devices can be used to assist with communication, controlling the environment, mobility and other activities of daily living. These devices have been commonly used for children with a variety of disabilities. Few devices are likely to be available off the shelf for children with complex physical and cognitive disabilities, so it may take some creativity to modify already existing devices, or create homemade devices, that fit the particular situation. Each school district should have an assistive technology specialist on staff or available as a consultant to help you. A few examples of assistive technology devices include:

### COMMUNICATION

- Picture communication boards allow a child who doesn't speak understandably to point to pictures to communicate desires and needs.
- Augmentative communication devices use computerized devices to provide a "voice" for communication.

### DAILY ACTIVITIES

- Devices that allow a person to turn something on and off. "The Clapper" is one such device that allows a child with mobility difficulties to turn a light on and off without getting up.
- Picture directions can be put on or near the place where a child must perform an activity.

- Mobility aids can help a person get around or participate in an activity that otherwise requires a motor skill the child finds problematic because of mobility or motor control difficulties.
- Specially designed recreational equipment can allow a child to participate in games or sports, such as a ball ramp to allow children to bowl who cannot pick up and move a bowling ball.

### EDUCATIONAL ACTIVITIES

- Large-button calculators to assist with math.
- Color-coded organizers to help identify what goes where.
- Speech recognition software and other computer software to enable a child to enter and read text.

To successfully use assistive technology for your child's IEP, make sure:

- the IEP team considers whether assistive technology may be beneficial for the child;
- the assistive technology device doesn't inhibit the child's development or reduce his/her skill level, but extends his/her capabilities;
- commercially purchased devices take into account any cognitive limitations the child may have;
- the parent, child and school personnel receive adequate training on the use of the device;
- service and maintenance are available for the device;
- back-up plans exist if crucial devices break down;
- the child's assistive technology needs are monitored regularly;
- all assistive technology devices are written into the IEP;
- the IEP team considers the child's assistive technology needs only after determining his/her educational goals;
- a person knowledgeable about assistive technology is on the IEP team;
- the device is sent home if the child needs the assistive technology at home;
- the child has a monitored trial period with the device to ensure it is functioning properly.

### INTERNET SITES

New IDEA

[www.ed.gov/offices/OSERS/IDEA/the\\_law.html](http://www.ed.gov/offices/OSERS/IDEA/the_law.html)

New IDEA regulations to implement the law

<http://idea.ed.gov>

Wrightslaw Special Education Advice and Resources

[www.wrightslaw.com](http://www.wrightslaw.com)

Project INSPIRE at Texas Women's University

[www.twu.edu/INSPIRE/](http://www.twu.edu/INSPIRE/)

PE Central at Virginia Tech (a variety of lesson plans and activities)

[www.pecentral.org](http://www.pecentral.org)

RESNA Technical Assistance Project

Information on state resources on assistive technology

202.857.1140

[www.resna.org/taproject/](http://www.resna.org/taproject/)

Parents, Let's Unite for Kids

Family guide to assistive technology

406.255.0540

[www.pluk.org](http://www.pluk.org)

National Association of School Psychologists

[www.naspweb.org](http://www.naspweb.org)

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## Common bonds unite the lives of those affected by MPS and related diseases—the need for support and the hope for a cure.

The National MPS Society is committed to making a difference in the lives of MPS families through support, research, education and advocacy. Families from around the world gain a better understanding of these rare genetically determined diseases through the Society's assistance in linking them with healthcare professionals, researchers and, perhaps most importantly, each other.

Individuals affected with an MPS or related disease and their families have a resource. One that stands ready to help—a resource that takes an active role in fostering the courage necessary to confront these diseases every day.

Benefits of membership in the National MPS Society:

- *Courage*, our quarterly newsletter containing stories and information about individuals with MPS and related diseases;
- Educational materials such as fact sheets and an MPS glossary;
- Conference and education scholarships;
- The Family Assistance Program, which provides financial support for durable medical goods;
- News about various Society sponsored conferences and gatherings, where families and leading MPS scientists, physicians and researchers join together for a common cause;
- Information on local events, such as regional social events and fundraisers. These events create opportunities for families to meet each other and help raise community awareness of these rare genetic diseases; and
- A listing in our annual directory of members that assists families to connect with one another.



For more information or to join the National MPS Society:

Visit [www.mpssociety.org](http://www.mpssociety.org)

Contact us at **877.MPS.1001**

Or email us at [info@mpssociety.org](mailto:info@mpssociety.org)