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ABSTRACT

The booklet offers guidelines to help parents of children with autism become more effective advocates for their children. Following a brief summary of parental rights in the education process, the booklet addresses special education and due process concerns. The hierarchy of procedures in bringing about a resolution of differences between parents and school districts is outlined. Services available from the Division of Developmental Disabilities for adults with autism are reviewed. A short list of suggestions for effective advocacy is followed by a discussion of parent rights and responsibilities under P.L. 94-142, the Education for All Handicapped Children Act. Basic characteristics of an effective advocate are noted along with summaries of advocacy-related services in New Jersey, national advocacy organizations, and four presentations on legislation. A brochure entitled "12 Month Education for Your Child" on how parents can request an extended school year program is attached. (CL)

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ADVOCATING FOR YOUR CHILD

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INTRODUCTION*

We persist because we love our children, they need us desperately and few others are willing to take up the fight. We persist because we fear what the future holds and time is short and barriers are great

We join together because we are few . . . our energy will someday wane, our supporters are limited, and we must make headway now, while we can.

We strive . . . because we know that the very lives of our children depend on it, and we must make change, for their sake, or they will die unseen, their beauty unappreciated, locked up, unloved and alone

June, 1986

*Reprinted from: Warren, F. (1978). The child as victim. *Journal of Autism and Child Psychology and Schizophrenia*, 10, 240-242.

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YOUR RIGHTS IN BRIEF*

IF YOU THINK YOUR CHILD IS HANDICAPPED, YOU HAVE:

- **The right** to have your child fully tested by your school district, at no cost to you.
- **The right** to see the results of this testing and all other records about your child.
- **The right** to have your school district consider the reports of people outside the district who have tested your child.
- **The right** to a written notice of the district's decision about your child's handicap and the reasons for the decision.

IF YOUR CHILD IS HANDICAPPED, YOU HAVE:

- **The right** to a free appropriate public education for your child
- **The right** to have your child educated in a setting which is as "normal" as possible.
- **The right** to have an Individualized Education Program (IEP) written for your child.
- **The right** to participate in the conference where the IEP is written.
- **The right** to have your child's IEP updated at least once a year.
- **The right** to have your child re-tested by your school district at least every three years

IF YOU DISAGREE WITH YOUR SCHOOL DISTRICT, YOU HAVE:

- **The right** to be fully informed about the reason for the school district's decision.
- **The right** to have your child tested by someone outside the school district at no cost to you.
- **The right** to a review of your disagreement by your district superintendent or a state Department of Education official.
- **The right** to a formal hearing and a decision by an independent administrative law judge
- **The right** to appeal the judge's decision in either state or federal court.

*Reprinted from. Special Rights for Special Children - A Manual For Parents of Handicapped Children in New Jersey. (1985) Education Law Center, Inc. Newark, NJ 07102

SPECIAL EDUCATION AND DUE PROCESS

Herbert D. Hinkle, Esq

The right to a free, appropriate, public education for children with autism is protected by both federal and state law. Regulations (N.J.A.C. 6:28) issued by the New Jersey Department of Education interpret these laws and provide standards that school districts must meet.

Appropriate Education

Every handicapped child between the ages 5 through 21 is entitled to a free, appropriate public education that is individually tailored to meet the child's unique needs. Handicapped children between the ages 3 to 5 are entitled to free, appropriate preschool programs tailored to meet individual need. No child can be denied an appropriate education because of the severity of the handicapping condition. Of course some children because their disabilities are mild and do not interfere with their ability to learn do not need special education.

Related Services

Every handicapped pupil is entitled to receive the related services needed to benefit from an appropriate education. Examples of related services include: transportation, physical and occupational therapy, counseling for the child and family, speech correction, and psychological services. This list is illustrative of the wide variety of services that a pupil might be entitled to receive, depending upon need. A word of caution: school districts sometimes prescribe the level of service based on what is available (e.g. physical therapy, one half hour twice a week) rather than what the child actually needs. Parents should be alert to this.

Residential Placement

School districts must provide residential programs whenever necessary for pupils to benefit from special education. Some autistic children require residential programs, especially those who need continuous reinforcement in order to retain what they learn. It is useful to bear in mind that because residential programs are expensive and must be paid for by the school district, many districts are reluctant to prescribe such programs and will refer parents to the Department of Human Services for residential placement. This is not a satisfactory alternative because Human Services can obtain reimbursement from parents for the cost of residential services while school districts cannot.

Extended School Year

School districts must provide extended school year programs whenever necessary to prevent a pupil from seriously regressing. The nature of the services required over the summer months varies with the unique needs of each child. Some children might require the same level of programming and related services as provided during the regular school year; others might require less.

Evaluation

Children thought to be in need of special education must be evaluated by professionals employed by the local school district. This will include assessments by the psychologist, social worker and learning disability consultant who comprise the child study team. In addition, a medical evaluation is required. If the child is thought to have a particular disability, such as autism, an expert in that field must participate in the evaluation. Parents can also share with school officials the results of any private evaluations they have obtained.

Parents who disagree with the results of this evaluation can request an independent evaluation at school district expense. The district must provide this evaluation, unless it requests a due process hearing and proves that a second evaluation is unnecessary.

Classification

Once evaluated, a pupil must be classified according to disability. New Jersey uses only 12 categories. (The amount of state aid that a district receives is determined by the classification assigned.) Unfortunately, autistic children do not fit squarely into any of the 12 existing categories. The category "neurologically impaired" is often assigned to autistic children.

Individual need and not the general category assigned should determine the services a pupil will receive. A district might operate a program for neurologically impaired pupils, but no child should be placed into such a program unless it can adequately meet the child's needs.

Individualized Education Plan (IEP)

Once classified, the child study team must meet with the parents to develop an IEP that is responsive to the needs of the pupil. The IEP must specify the education and related services the child is to receive, their frequency and duration, and where those services are to be provided. If extended school year programming is necessary, the IEP should spell this out. The IEP should also state the child's educational goals for the year and tell how they will be measured. The more explicit the IEP, the better.

Parents should be wary of agreeing to any IEP that has been prepared in advance of their first meeting with the child study team. Under no circumstances should they sign an IEP if they disagree with it or if a critical element is missing. If the parents refuse to sign the IEP, before it can be implemented the school district must request a due process hearing and prove the IEP is adequate.

School districts have 90 days from the time a child is first identified to conduct an evaluation, classify the child, prepare the IEP and begin providing services. The law does not allow school districts to place children on waiting lists for services or otherwise delay implementing any portion of the IEP.

Due Process

Parents can use due process procedures to challenge any major decision that negatively affects their child's education. Parents can challenge evaluation results, classification, the IEP, the adequacy or efficacy of services provided, and placement. Parents can do this by requesting a hearing in writing from the New Jersey Department of Education. A settlement conference must be held within 7 days, and if this fails to resolve the dispute, a hearing before the Office of Administrative Law must be held within 14 days. The results of this hearing can be appealed to the courts. Dispute resolution and mediation procedures are also available to help resolve differences informally.

Laws are not self-enforcing, and parents should not rely upon the good faith of school districts to carry out what the law requires. Even the best school district might incorrectly assess a child's needs or let economics control the decisions it makes. Parents should familiarize themselves with their rights under the law and not hesitate to exercise them when the need arises.

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STEPS INVOLVED IN RESOLVING A DISPUTE BETWEEN PARENTS AND THE SCHOOL DISTRICT

The following represent a hierarchy of procedures involved in bringing about a resolution between yourself and the school district. Make sure you follow procedure: do not attempt to pass over any of the steps outlined below. Most disputes are settled before they go to due process hearings through informal proceedings. Therefore, always attempt to resolve the dispute informally; if you are unable to do so, you may begin to pursue a more formal course of action.

- A. Speak with the *Supervisor* of the Child Study Team. If you cannot come to an agreement,
- B. Speak with the School District Superintendent of Special Services. At this time in the series of contacts, it is important that you also contact the Division of Advocacy for the Developmentally Disabled, (609) 292-9742, or some other advocacy-related service and explain the case. If an agreement still has not been reached,
- C. Request a Mediation Conference through the County Supervisor of Child Study. This person should listen to both sides and explore the options in an effort to bring about resolution prior to filing for a hearing.
- D. Contact the Director of Special Education, NJ Department of Education, Trenton, to request due process. The first step is a settlement conference. A settlement officer will mediate a discussion and suggest a solution. If an agreement is reached, it is documented and signed at that time. If an agreement is not reached, a Due Process Hearing is conducted by an Administrative Law Judge, who after hearing both sides, writes a formal opinion giving his/her decision and the reason for it. It is helpful to have a lawyer represent you. If you must take this step, make sure to call the Public Advocate's Office at Step B above, or some other advocacy-related service.

SERVICES FROM THE DIVISION OF DEVELOPMENTAL DISABILITIES AND DUE PROCESS

Herbert D. Hinkle, Esq

As a general rule, people with autism do not usually turn to the Division of Developmental Disabilities (DDD) for services until age 21 when they are about to leave the special education system. In some instances school age pupils might receive additional services, such as group home placement or respite care through programs sponsored by the Division of Youth and Family Services (DYFS) but for the most part, the special education system is the chief service provider for autistic children. Thus the focus of this article is on the adult person with autism seeking services or already receiving services from DDD.

DDD is undergoing tremendous change because of 1985 legislation that expanded the jurisdiction of the then Division of Mental Retardation to serve all developmental disabilities. Precisely how this will effect persons with autism is not completely settled as this article is being written, and persons seeking services from DDD for the first time should contact COSAC for up-to-date information at the time they make application for service. The change in the law should not effect persons already receiving service from DDD.

Eligibility For Services

Eligibility for services is based upon a finding by DDD that the client is developmentally disabled *and* in need of specialized services because of that disability. (N.J.S.A. 30:4-25.1, et. seq and N.J.S.A. 30:6D-23, et. seq.) The exact services that eligible clients are entitled to receive is determined by their individual needs.

Currently under the law, DDD is mandated only to serve eligible, mentally retarded clients. By executive agreement, DDD also has a mandatory responsibility to provide services to adult autistic clients. With regard to all other developmentally disabled persons, DDD is not mandated to serve them until April, 1988. At that time, DDD will also have responsibility toward autistic children as well as adults. Whether this means that DDD will replace DYFS as the provider of ancillary services to school age pupils remains to be seen.

Services Available From DDD

DDD provides a variety of services that include case management, guardianship, respite care, day programming, and residential placement in

institutions (this is becoming increasingly rare as institutions shrink in size), and community residential programs.

Day programs include placement in adult activity centers. People with greater employment potential than activity center clients are frequently served in work activity centers and sheltered workshops sponsored by the Division of Vocational Rehabilitation Services (DVRS) and not DDD. (The admissions process and the appeals procedure for services from DVRS are similar to those of DDD.) In recent years, DDD has initiated a number of employment related programs for its clients that can lead directly to competitive employment without DVRS involvement.

As mentioned, residential placement can include institutional as well as community placement. DDD sponsors a wide array of community residential programs that include family care homes, skill development homes, group homes, supervised and unsupervised apartments.

Unfortunately, there is a shortage of community residential placements in New Jersey. DDD has developed a waiting list arrangement giving priority to those most in need, particularly those who will significantly regress or cause injury to themselves without residential placement. This arrangement is described in DDD Circular Number 8. The legality of the waiting list has not been tested in the courts.

Habilitation Rights

The New Jersey Developmental Disabilities Rights Act (N.J.S.A. 30 6D-1, et. seq.) provides that "every service for persons with a developmental disability . . . shall be designed to maximize . . . developmental potential . . . and shall be provided in a humane manner in accordance with generally accepted standards . . . and with full recognition and respect for the dignity, individuality and constitutional, civil and legal rights of each person . . . and in a setting and manner which is least restrictive of each person's personal liberty."

This law applies to all DDD services regardless of whether they are residential or day, community or institutional. The DD Act applies to all agencies providing services to persons with developmental disabilities, including DYFS and DVRS.

Individualized Habilitation Plans (IHP)

The IHP serves as the cornerstone in the implementation of rights under the DD Rights Act. Just as with the IEP described in the article on special education in this booklet, every client must have an IHP which must be updated annually. The IHP must specify habilitation goals, methods of attaining those goals, criteria for measuring progress, and the persons res-

possible for implementing the IHP. N.J.S.A. 30:6D-11 The IHP must be developed in consultation with the client, and the client's family or guardian.

Whenever a client is to be transferred from one residential program to another, an updated IHP must be prepared at least thirty days prior to transfer, to allow the client and family to visit the new site and to file an appeal in the event they believe the new program inadequately meets the client's needs. N.J.S.A. 30:6D-16.

Artistic people receiving services from DVRS are entitled to an Individualized Written Rehabilitation Plan (IWRP) The principles behind this plan and the procedure for developing it are largely the same as for the IHP and the IEP.

Due Process

Persons or their representatives who believe they have been wrongly determined ineligible for services from DDD, or who believe they are not receiving appropriate services are entitled to use the DDD appeal procedure to challenge DDD actions.

DDD Circular Number 37 describes this procedure in detail. It begins with informal discussions on the local level and proceeds to a higher level if necessary. If this fails to resolve the complaint, a hearing is held before a DDD appeals officer. This is much like a court trial except less formal. The decision of the appeals officer can be appealed to the courts. The DD Rights Act also permits parties to go directly to court, bypassing the DDD appeals process.

The IHP can play an important role in the appeal procedure. It is often difficult to convince a judge or hearing officer that a program is deficient unless it appears grossly deficient. Judges and hearing officers do not want to second guess service providers. However, if the IHP identifies services that are not being provided, it is much easier to prevail. The judge or hearing officer is not being asked to determine what is most appropriate, but rather to order the service DDD has already acknowledged in the IHP to be necessary. Consequently, clients and their families are well advised to insist that the IHP specify in detail what services the client needs, and not agree to an IHP that is incomplete or vague. An IHP is very much like a contract and can be enforced through the appeal process.

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ADVOCACY TIPS

Kathleen Meyers
The Bancroft School

REMEMBER — YOU CAN MAKE A DIFFERENCE

DO YOUR HOMEWORK

Become Knowledgeable About Autism

Determine The Needs Of Your Child
(Independently From An Existing Program Option)

Know Your Rights And The Rights Of Your Child

Know The Law - Request (in writing) a copy of state and federal regulations from your local school district or child study team

Prepare For Meetings

Visit And Evaluate Program Alternatives

Get On Mailing Lists Of Relevant Organizations To Receive Up-to-Date Information On The Law, Meetings Of Interest, Conferences, Workshops, etc.

BE ASSERTIVE

Make *Positive* Contact

Be Direct, Specific, And Confident - Make sure your requests/statements are clear and straight-forward

Take A Calm, Reasonable Approach

Listen Actively

Ask For Clarification On *Anything* You Do Not Understand

Independently Verify Information

Maintain Regular Contact

FOLLOW PROCEDURE

Know What Channels Exist

Work Through Existing Channels *First*

Document Your Efforts And Their Results

THINK AHEAD

Document Everything - Correspond in writing. Make records of phone calls. Take notes and keep them. Retain copies of records.

Plan Ahead - Be realistic and patient - Don't expect too much too soon — Remember . . . Waiting lists exist!

Work Through The Legal Structure - Establish positive relationships with key government officials, business leaders, and civic leaders. Get involved in the selection of policy makers. Participate in letter writing campaigns.

Conduct Public Information Campaigns - Improve public opinion and foster community acceptance by providing consistent *positive* messages about persons with autism and their capabilities through media releases, information brochures, and a speakers bureau.

Unite Your Efforts - Join a relevant organization, and/or a parents group. If none exist, start your own. A united front is a powerful force which officials cannot ignore - Remember, there is strength in numbers.

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ADVOCACY - WHAT PARENTS NEED TO KNOW

***P.L. 94-142**, The Education For All Handicapped Children Act, gives parents the right and responsibility to be involved in educational planning for their child. The law which ensures all handicapped children a free appropriate education in the least restrictive environment mandates active parent involvement in the education of their children primarily through the process of developing an Individualized Education Plan (IEP).

In order to effectively use this law, parents must not only understand all the relevant provisions, but must also learn the art of effective advocacy.

****WHAT ARE MY RESPONSIBILITIES AS A PARENT IN THE PROCESS OF OBTAINING AN EDUCATION FOR MY HANDICAPPED CHILD?**

Parents often feel that the responsibility for the education of their child rests entirely with the public school system. In fact, many parents consider the school personnel to be experts and therefore to know what is best for their child. While this may be the case for certain aspects of the child's program, as a parent you have the responsibility to be an advocate for your child. Do not be intimidated by thinking that school personnel are experts. You, too, are an expert when it comes to the needs of your child.

Federal and state laws make it mandatory for you as a parent to be included as part of the team that makes educational decisions for your handicapped child. It is your responsibility to work on that team to develop an appropriate educational program for your child. It is helpful to remember that everyone on the team is working together for the same purpose - to provide for your child's educational needs. In accepting this responsibility, some of the following suggestions may be helpful:

- Maintain a cooperative attitude. Working together in a team effort will only serve to benefit your child.
- Learn as much as you can about your rights and the rights of your child.
- Ask questions. Since educational and medical terms can be confusing, it is perfectly acceptable to question what is being said about your child.
- Express your concerns about your child's education. School personnel will welcome your observations and suggestions.

- **Join a parent organization.** It is often helpful to know that other parents are going through similar experiences. The opportunity to share knowledge and experiences can be invaluable. Many times parents find that as a group they have the power to bring about needed changes. A parent group can be an effective force on behalf of your child.

*COMPONENTS OF 94-142

The following represent the important concepts embodied in 94-142. An understanding and working knowledge of the law is essential in developing effective advocacy skills and should be part of any program designed to teach parents to be advocates.

- **Notice** - Parents have the right to be contacted before an evaluation of their child for special education services, when the IEP is to be written or amended, and before placement is made or changed. In other words, parents must be notified before any action can be taken regarding their child's educational program.
- **Consent** - Parents must consent to any change in their child's placement.
- **Evaluation** - The first step in planning the child's educational program is an evaluation completed by qualified school personnel in order to determine the child's unique needs and current level of functioning. This provides the basis for an IEP. Parents also have the right to an independent evaluation by a person outside of the school which may be at the school's expense.
- **Records** - Parents have the right to see records kept regarding their child. These records may include test results, teacher's reports, or any information the school has regarding the child. These records should be private, between the parents and school officials directly involved in the education of the child.
- **IEP** - Parents not only have the right to be involved in the development of an IEP, but should be a vital part of the IEP team. The IEP is the heart of 94-142 and the main focus of a training session should be effective use of the IEP process. A more detailed explanation of the IEP will be given below.
- **Least Restrictive Environment** - Your child has the right to be educated with non-handicapped children to the maximum extent possible. This obviously does not mean all handicapped children should be attending all classes with non-handicapped children. It does mean that handicapped children should be educated with non-handicapped children whenever possible.

- **Right To Appeal** - Parents are afforded an opportunity under 94-142 to appeal decisions made by the school officials with which they disagree. (i.e. denial of services on the IEP, inappropriate placement, etc). Parents are entitled to an impartial due process hearing on contested issues before a hearing panel whose members should not have a personal or professional interest in the outcome of the appeal. In order to allow parents to effectively use the appeal process, the school district must provide parents with written notices about decisions made. This information should include rights regarding appeals.
- **Individualized Education Plan** - The IEP is developed by a team which may consist of the child's teacher, other school personnel such as a principal or Special Education Director, a social worker or psychologist, language therapist, or anyone who may have important information necessary for planning the child's program.

The IEP consists of the child's educational goals in different skill areas, and "objectives" which are means by which these goals are to be achieved. For example, a goal may be to increase appropriate social behavior with peers. The objective may read, "Sammy will appropriately play a board game for five minutes with a non-handicapped peer." The technique for implementation should also be included. Chapters may keep sample IEP's which parents may use as a reference.

After notice has been given to the parent and the IEP meeting is set for a mutually convenient time, there are a number of things the parent may do to prepare for the IEP meeting. First and foremost, the parents should realize that they know their child better than anyone and are a vital part of the development of his/her program, and the child is entitled to whatever services are necessary in order for their child to benefit from the IEP. With this knowledge, parents should prepare to write the IEP in a way that will provide their child with the opportunity to maximize his/her potential for independent living.

**In addition, you should know that:

- A child cannot receive special education and related services nor be placed in a special education class without an IEP that you help develop
- The placement of a handicapped child cannot be changed without a new IEP.
- If a hearing is requested to determine a child's placement, the child must remain in his or her current placement until the decision has been made.

- Transportation should be included in your child's IEP as a related service.
- The IEP is not intended to cover all of the needs of a handicapped child — only the educational needs

Many other rights are included under Public Law 94-142. Learn your rights in order to insure that your child receives an appropriate public education.

***PREPARING FOR THE IEP CONFERENCE

Before the conference, you should prepare by gathering all the information you will need and then organizing your ideas, so that you can be as effective as possible in helping to plan your child's program. The following is a checklist of questions you should ask yourself as you prepare:

- Have I read all the records the school district has concerning my child?
- Has my child been tested by the different professionals who are required to perform evaluations according to the child's classification?
- Do I have copies of any school records which I may need (evaluation reports, previous IEP's)?
- Have I made notes of anything in the evaluation reports which I don't understand or with which I disagree?
- Have I sent copies of any reports of examinations or testing which have been done privately to the child study team for them to study the reports before the conference?
- Have I reviewed last year's IEP (if any) to see where it might be out of date or incomplete?
- Have I made a list of all the subjects which I think should be discussed at the IEP conference, such as:
 - What kind of things my child is ready to learn
 - What my child is interested in
 - What problems, if any, I am aware of with my child's current program.
 - Any related services which my child needs but is not receiving.
 - What my child's needs are in the way of preparation for future employment, such as vocational school or a pre-vocational work skills program

- Have I shared my ideas and thoughts with friends, relatives, or others who know my child, and asked for their suggestions?
- If there is someone whom I would like to take to the IEP conference with me, have I made the necessary arrangements with that person?

While you are taking these steps to prepare for the IEP conference you should make a real effort to concentrate on your child's future education and not on any problems you have had in the past. You won't accomplish anything by bringing these problems up at the conference, so there is no point in wasting your time thinking about them now. Even if you and the school district have had serious conflicts or differences of opinion, try to put them behind you and focus all your attention on what you feel your child needs for the next year.

***WRITING THE IEP**

1. **Present Level of Functioning** - The initial step in drafting the IEP should be a determination of the present levels of functioning in different skill areas such as Language/Communication, Behavior, Survival Skills, Academics, Pre-Vocational/Vocational, Self-Care. Parents should make sure that their knowledge of the child's functioning in certain areas is written down on that form. Children with autism, particularly, often keep their talents hidden to all but their parents. A sentence about functioning may read, "Parents report Johnny speaks in four-word sentences."

These levels of functioning are the basis of determining goals and objectives. All relevant information should be used in determining levels of functioning. This can include the child's school work, observation of teachers, parents, relatives and friends, results of formal and informal assessments.

Anything identified as a weak area in the level of functioning should be a goal. If Johnny attends to a task for 30 seconds, increased time on task should certainly be part of the IEP.

2. **Related services** are defined as any developmental, corrective and other supported services required to assist a handicapped child to benefit from the special education program. The school must provide these services if it is determined by the IEP team that they are needed. The IEP should include the specifics of delivery of the related services, how long it will last, how many times a week, who is going to give it.
3. Your child's IEP should reflect a program of high expectations, should be challenging, and age-appropriate.

4. Do not allow your request for services to be written in the "comments" section of the IEP form. The school may later argue that they do not have to provide that service because it is not written as part of the goals and objectives.
5. Implementation of goals is a crucial part of a child's educational program. Without proper implementation, the IEP means nothing. Again, clarify what service the child will be provided, what methods or approaches will be used. Do not feel limited by the IEP format. If necessary, write an addendum.
6. If you arrive at the IEP meeting and the IEP is already written, state that you wish to go through it. Feel free to suggest any changes you feel are necessary and explain.
7. Do not allow those present to rush you through the IEP meeting. If the school personnel only have 30 minutes and you need more time, schedule another meeting.
- ***8. (In New Jersey, the Public Advocate advises that you do not sign the IEP if you do not agree with it or do not clearly understand its contents. Get advice on what to do by calling the Public Advocate at (609) 292-9742, or some other advocacy-related service.)
9. Do not let school personnel tell you they do not offer whatever your child needs. If it is determined that your child needs a specific service to benefit from his/her program, this service must be given by the school or they must contract with a private agency to deliver the service.

****AS THE PARENT OF A HANDICAPPED CHILD, WHAT SHOULD I DO TO PREPARE FOR WORKING WITH THE PUBLIC SCHOOL SYSTEM?**

As you begin the process of obtaining a public education for your handicapped child, you will find it necessary to work with many different school personnel. The following suggestions may make it easier and faster to obtain the desired educational services:

- Make all requests in writing.
- Keep copies of all correspondence you send and receive.
- Keep a diary of names and dates of telephone conversations, letters, and appointments
- Request copies of all reports on your child for your files.
- Ask as many questions as it takes to understand what is being said about your child, and keep notes for future reference.

- Explain your concerns about your child. Remember that you know your child better than anyone else. Your comments will be helpful.
- Keep an open mind. When there is a spirit of cooperation between you and the school, you will find that the results come much faster. Try to understand all viewpoints before making a decision.

WHERE CAN I TURN FOR HELP AND FURTHER INFORMATION?

To insure that you are well informed of your rights, you should obtain a copy of Public Law 94-142 from your congressional representative. You may also find it helpful to obtain a copy of your state's current special education laws and regulations from the Special Education Division of the State Department of Education. Your school principal or special education administrator will be able to inform you of local school policies as well as your rights under the law. Joining a local parent organization can provide you with needed support. In addition, the parent group may know of other local resources. Information about local parent organizations can be obtained from Closer Look, The National Information Center for the Handicapped, P.O. Box 1492, Washington, DC 20013.

For answers to specific questions about the educational rights of your handicapped child, contact The Council for Exceptional Children, 1920 Association Dr., Reston, Virginia 22091.

*Reprinted from Goodman, S. (1986) Advocacy Under 94-142: Parents Helping Parents. The Advocate, the newsletter of the National Society for Children and Adults With Autism.

**Prepared by: Mack, Jean (1981). Parents' Rights and Responsibilities. ERIC Clearinghouse on Handicapped and Gifted Children.

***Reprinted from: Special Rights for Special Children: A Manual for Parents of Handicapped Children in New Jersey. Education Law Center, Inc., Room 209, 155 Washington St., Newark, NJ 07102.

****Included by. The Autism Outreach Project.

WHAT IS AN EFFECTIVE ADVOCATE?*

Barbara Coyne Cutler

Of course, you are thinking, I want to help my child get the education he needs and is entitled to. But don't you have to have professional skills and special knowledge to be an advocate? Don't you have to be some kind of recognized expert to do the job? How can I, a mere parent, become an effective advocate? After all, I've often heard lawyers referred to as advocates, and they are experts in interpreting the law.

It may help you to know that there have been lawyers who have looked to skillful and knowledgeable parent advocates for advice in dealing with school systems. These parents were not professionals, just good advocates who learned through hard work and practice how to do the job well. Any parent can become a good advocate.

The following represent the basic characteristics of a good advocate:

1. ***GREATER CONCERN FOR THE CHILD'S BEST INTERESTS THAN FOR THE CONCERNS OR INTERESTS OF THE SCHOOL SYSTEM***

Who cares more than you about what is happening to your child and what the future will hold for her? Yes, there may be many professionals and other outside advocates who care about your child and who are on your side, but they probably have tens or hundreds of other students or clients to be concerned about. As a parent, your love and concern is deeper, stronger, and more enduring.

2. ***LONG-TERM COMMITMENT TO THE CHILD'S WELFARE AND TO BEING THE CHILD'S ADVOCATE***

Who has been and will be around your child longer than you? Professionals come and go, sometimes yearly, and they sometimes leave when you feel you need them most. That teacher who was so kind and interested has just moved to another part of the country, or that sympathetic psychologist has opened a practice a hundred miles away. You, however, will be there with your child throughout her educational career, and beyond if she needs you.

3. KNOWLEDGE OF THE PRESENT NEEDS OF THE CHILD OR THE ABILITY TO RECOGNIZE THOSE NEEDS

Who knows more about your child's growth, personality, special needs, and special skills than you? You know how hard she tries to do certain things how well she gets along with the neighborhood children, or how lonely she feels watching life go on around and without her. You are the best source of information about your child: You are the expert in residence. As useful as medical and school records are, they explain only part of your child's experiences. You are the best available expert with the broadest overview of your child.

4. ASSERTIVENESS IN POINTING OUT THE CHILD'S NEEDS TO THE PEOPLE RESPONSIBLE FOR MEETING THOSE NEEDS

All that being assertive means is speaking up and hanging in. Some of us are better (and bolder!) than others. But even if you are shy or lack confidence, you can learn to be more assertive. You may already be feeling a little surge of confidence from realizing that as the natural advocate, you have some powerful qualifications that no one else can match.

5. ABILITY TO WORK WITH OTHERS (PROFESSIONALS, PARAPROFESSIONALS, AND OTHER PARENTS AND ADVOCATES) TO DEVELOP APPROPRIATE AND BENEFICIAL EDUCATIONAL GOALS AND PLANS FOR THE CHILD

Working with others is something you have done before, but you may have yet to work as equals with school personnel. Luckily, school people react in the same way as anybody else to praise, diplomacy, or persuasion. Your ways of dealing with pleasant and unpleasant coworkers will help you work with school people of both sorts. After you have rid yourself of some ideas you may have about "mere" parents and about experts who have all the answers, you will become comfortable in your working relationships with professionals. You will be drawing on your everyday experience and skills to learn how to cooperate with, disagree with, and, once in a while, even manipulate school people.

6. ABILITY TO FIND AND USE INFORMATION, ALLIES AND RESOURCES TO PUT THE NEEDED EDUCATIONAL PLANS TO WORK

Some of you may feel sure that you are especially weak in obtaining information and discovering allies and resources, but all of you have some skills in this area even if you haven't applied them to getting educational services for your child. For example, you used the direc-

tions and guarantee for the toaster; if you couldn't understand these papers, you probably asked the right friend to explain them to you; and if your friend suggested that you write to the company or the Better Business Bureau, chances are, you followed up on the idea. These are your everyday skills which are the basis for developing special advocacy skills for finding and using information, allies, and resources.

This list may seem overwhelming, but note that there is nothing in it which says you need to be a lawyer, an educator, or a doctor. It includes only personal characteristics which you may already have, can strengthen and adapt, or can acquire with some self-instruction and practice.

As you use the skills which you will be learning or improving, you will keep getting better at using them. You will become more relaxed about or at least less frightened of your meetings with the professionals. It will never be really easy, and you can never become casual about any meetings that will affect your child's education. You will, however, derive great satisfaction from your personal successes as an effective advocate, and even greater satisfaction from the improvements in your child's education that result from your advocacy.

Editor's Note. The characteristics described above apply not only to those parents seeking to secure an appropriate education for their child who has a developmental disability, but also to those parents seeking to obtain other necessary services, to ensure their child's progress towards greater independence throughout their adolescence and into their adult lives.

*Reprinted with permission from: Cutler, B.C. (1981). *Unraveling the Special Education Maze*. An Action Guide for Parents. (PP 5-8) Champaign, IL: Research Press.

SUMMARY OF ADVOCACY-RELATED SERVICES IN NEW JERSEY*

THE DIVISION OF ADVOCACY FOR THE DEVELOPMENTALLY DISABLED

The Division of Advocacy for the Developmentally Disabled (DADD), N.J. Department of the Public Advocate, protects and advocates for the rights of persons with developmental disabilities. DADD gets involved in a number of areas affecting the lives of persons with developmental disabilities, including special education, vocational rehabilitation, habilitation, and more. Individuals who have a developmental disability, as well as their family members, are eligible for the following services (free of charge)

Information

- about the rights of persons with developmental disabilities, and those of their parents
- on the major laws affecting persons with developmental disabilities.
- regarding the types of services a person with a developmental disability can get, and . . .

Assistance

- in finding the services a person with a developmental disability is eligible for and referral of that person to the appropriate agency
- in understanding the major laws affecting persons with developmental disabilities and their rights under the law
- in deciding what avenue of recourse to take to resolve certain conflicts.
- in resolving certain disputes

Investigation

- of a valid complaint involving the violation of a developmentally disabled person's right or the denial of a service to which they are entitled.

Negotiation

- of a solution on behalf of clients, if the complaint was valid.

Representation

- at the discretion of the Public Advocate, the interests of clients at a legal proceeding.

Lectures

- on various advocacy/legal issues by staff representatives to interested parent groups, organizations, etc.

The Division of Advocacy for the Developmentally Disabled is dedicated to providing advocacy and legal assistance to persons with developmental disabilities of all ages, in an effort to ensure that they are freely granted their rights under the law and afforded the same opportunities in life as nonhandicapped persons.

THE COMMUNITY HEALTH LAW PROJECT

A non-profit corporation called The Community Health Law Project provides legal and advocacy assistance to persons residing in certain counties who have a psychiatric impairment or who cannot afford an attorney, and to residents statewide who are physically or developmentally disabled. Services provided by The Community Health Law Project include representation and counseling in:

Governmental and Public Assistance Benefits -

- SSI
- SSD
- Welfare
- Medicaid
- Medicare

Family -

- Custody
- Visitation
- Support

Housing -

- Landlord Tenant
- Boarding Homes
- Zoning

Consumer -

- Debt Collection
- Budgeting
- Contracts

Referral To -

- Mental Health Agencies
- Community & Service Agencies

Counseling -

- In asserting rights in cases of discrimination, expungement of commitment records, rehabilitation, divorce, and Social Services.

Most services are provided free of charge to eligible persons through the Community Health Law Project.

For further information or assistance, call The Community Health Law Project nearest you.

55 Washington St
East Orange, NJ
(201) 672-6050

240 West State St
Trenton, NJ
(609) 392-5553

60 Prince St.
Elizabeth, NJ
(201) 355-8282

530 Cooper St
Camden, NJ
(609) 964-0030

EDUCATION LAW CENTER, INC.

The Education Law Center, Inc. (ELC) is a nonprofit, public-interest law firm specializing in reform of the public elementary and secondary school systems in New Jersey and Pennsylvania. The Education Law Center provides free legal assistance to parents, students, their organizations, and concerned individuals who encounter individual or systemic problems in public school education. Litigation undertaken by ELC deals with issues of broad public importance, especially as such issues impact on children-at-risk — poor children, minority children, handicapped children

The activities of ELC are directed primarily toward resolution of issues involving:

- equal educational opportunity for all public school students regardless of race, sex, national origin, mental or physical handicap, socioeconomic status, or geographic location;
- provision of a "thorough and efficient" education, as required by state constitutions, through equalization of local districts' financial resources, establishment and attainment of student performance goals, provision of compensatory or remedial programs, creation of alternatives to traditional classrooms and methods, and other means.
- confidentiality of and access to pupil records and the right to challenge incorrect information in such records;

- due process rights of parents and students with regard to disciplinary actions and special education placements;
- provision of bilingual/bicultural programs and services for children of limited English speaking ability;
- parental and citizen participation and involvement in the education decision-making process of school systems;
- prevention of formal and informal exclusion of children from public schools; and
- educational rights of children in state county institutions or in other residential or special placements.

Parents, students and their organizations are encouraged to discuss their problems and concerns in the area of public education, by writing or telephoning:

Education Law Center, Inc.
 155 Washington Street
 Room 209
 Newark, NJ 07102
 (201) 624-1815

or

Education Law Center, Inc.
 2100 Lewis Tower Building
 225 South 15th Street
 Philadelphia, PA 19102
 (215) 732-6655

*Information adapted and reprinted from: Informational materials obtained through DADD, and brochures published by the Community Health Law Project and the Education Law Center, Inc.

**NATIONAL ADVOCACY
ORGANIZATIONS/AGENCIES SERVING
CHILDREN AND ADULTS WITH
DISABILITIES AND THEIR FAMILIES**

**Closer Look/Parents' Campaign
for Handicapped Children**
1201 16th St., N.W.
Washington, DC 20036
(202) 882-7900
(800) 522-3458

**National Coalition for Parent
Involvement in Education**
300 North Washington Street
Alexandria, VA 22314

**National Society for Children and
Adults With Autism (NSAC)**
1234 Massachusetts Ave., N.W.
Washington, DC 20005
(202) 783-0125

National Autism Hotline
Autism Services Center
Douglass Education Bldg.
Tenth Ave., & Bruce
Huntington, WV 25701
(304) 525-8014

**National Information Center on
Handicapped Children & Youth**
P.O. Box 1492
Washington, DC 20013
(703) 522-3332

**Disability Rights Education and
Defense Fund, Inc.**
2212 Sixth Street
Berkeley, CA 94710

**National Organization on
Disability**
2100 Pennsylvania Ave., N.W.
Washington, DC 20037

**Coordinating Council for
Handicapped Children**
220 S. State St., Room 412
Chicago, IL 60604
(312) 939-3513

**Parent Educational Advocacy
Training Center**
228 Pitt St., Suite 300
Alexandria, VA 22314
(703) 856-2953

THE LEGISLATIVE PROCESS

*The government of the State of New Jersey, like that of the United States, is divided among three co-equal branches: the legislative, the executive, and the judicial. The principal function of the Legislature is to enact the laws, or to change or repeal an existing law. The Executive branch carries out the law (including carrying out programs established by law). The Judicial branch interprets the law, punishes violators of the law, settles controversies and disputes, and is the final authority on the meaning and constitutionality of laws.

On the **FEDERAL** level, the three branches of government are:

- The Congress - (legislative)
- The President (including various cabinet level departments) - (executive)
- The Supreme Court and lower federal courts - (judicial)

The three branches of government at the **STATE** level are.

- The New Jersey Legislature - (legislative)
- The Governor (including various cabinet level departments) and state agencies - (executive)
- The New Jersey Supreme Court and the lower state courts (judicial)

Parents and other concerned advocates can influence the path of legislation through their active participation in the legislative process at both the state and federal level. Through their active participation in the legislative process, they can effectively shape the commitments of their state Legislators and the members of Congress, and in turn, positively influence the lives of children with developmental disabilities.

In order to be an effective legislative advocate, it is important to familiarize yourself with the legislative process at all levels of government. The information that follows explains the path that legislation must take in order to become a law at both the state and federal level.

****THE PATH OF LEGISLATION IN NEW JERSEY**

A proposal to make a new law, or to change or repeal an existing law is presented to the Legislature as a *bill*. To become a law, a bill must pass both houses by majority vote and be approved by the Governor.

Idea Developed

A legislator decides to sponsor a bill, sometimes at the suggestion of a constituent, interest group, public official, or the Governor. The legislator may ask other legislators in the same house to join as co-sponsors.

Bill Drafted

At the legislator's direction, the Office of Legislative Services, a non-partisan agency of the Legislature, provides research and drafting assistance, and prepares the bill in proper technical form.

Bill Introduced

The legislator gives the bill to the Senate Secretary or Assembly Clerk during a session. The bill is numbered, given first reading (the title is read aloud), printed and released to the public.

Committee Reference

The Senate President or Assembly Speaker usually refers the bill to a committee for review, but may send the bill directly to second reading in order to speed its consideration.

Committee Action

When scheduled by the chairman, the committee considers the bill at a meeting open to the public. The committee may report the bill to the house as is, with amendments, or by a substitute bill. If not considered or reported, the bill remains in committee.

Second Reading

When the bill is reported to the floor (or referred directly without committee review), its title is read aloud for second reading. The bill is eligible for amendment on the floor. After the bill is given third reading, the house must vote to return it to second reading for any further amendments.

Third Reading

When scheduled by the President or Speaker, the bill is given third reading and considered on the floor. The bill may not go through second and third reading on the same day, except by emergency vote of $\frac{3}{4}$ of the members (30 votes in the Senate, 60 in the Assembly).

Vote

The bill passes when approved by a majority of the authorized members (21 votes in the Senate, 41 in the Assembly) and is sent to the other house. If a final vote is not taken, the bill may be considered at another time or may be returned to a committee by a vote of the house.

Second House

The bill goes through a similar process. If the second house amends the bill, it is returned to the first house for a vote on the changes. A bill receives final legislative approval when it passes both houses in identical form.

Governor

After final passage, the bill is sent to the Governor. The Governor may sign it, conditionally veto it (returning it for changes) or veto it absolutely. The Governor may veto single line items of appropriation bills. Bills passed in the last 10 days of a 2-year session may be "pocket vetoed."

Law

A bill becomes a law upon the Governor's signature or after 45 days if the Governor takes no action. If vetoed, a bill becomes law if the Legislature overrides the veto by a $\frac{2}{3}$ vote (27 in the Senate, 54 in the Assembly). A law takes effect on the day specified in its text.

*****THE PROCESS OF A BILL BECOMING A LAW AT THE FEDERAL LEVEL**

A Representative may introduce a bill any time the House is meeting by placing it in the "hooper" beside the desk of the Clerk of the House. The name of the sponsor will be on the bill, and a public bill may have up to 24 co-sponsors. Bills are introduced more formally across the Capitol in the Senate. A Senator will rise and, when recognized, request permission to introduce a bill(s).

Introduced bills are assigned a number preceded by the appropriate letters: S in the Senate and HR in the House of Representatives. The bill is referred to a committee for study and possible action. Within each committee are subcommittees and the committee chairman will assign the bill to the appropriate subcommittee. Subcommittee and committee chairmen are the keys to proposed legislations. They either can schedule a bill for a hearing or not, and they can determine in what order proposed legislation will be taken up. If these two crucial chairmen are for a bill, it stands a good chance of favorable consideration by the committee; if they are not, the bill has little chance even to be considered, let alone be approved.

If the subcommittee puts a bill on its agenda for study, there will be public hearings at which witnesses may testify for or against the proposed legislation. Subcommittee meetings almost always are open to the public, so anyone may attend and listen.

After the subcommittee approves a bill, it is sent back to the full committee for approval. There it can be amended or re-worked. Full committee

meetings usually are open to the public. If the full committee approves a bill it is sent to the house for a vote. Depending on the rule being applied for the debate, most bills are open to amendment from the floor

Along with the approved bill, the committee also prepares a committee report to accompany the proposed legislation. The report describes the purpose of the bill and the reasons for its recommended approval by the full house. Further, the report gives a section by section analysis and states what each section accomplishes. Reports are assigned numbers and quantities are printed up by the Government Printing Office. Committee reports are invaluable for understanding what the bill is intended to do. They are used extensively by the courts, executive departments and agencies, and the general public.

After one house of the Congress has passed the bill, it is sent to the other house for approval. There, it goes through the same subcommittee-committee process before being brought up for a vote. If the bill is defeated, that is the end of it for the moment. If the bill is approved, it goes to the President for his signature at which time it becomes a public law. Should the President veto the bill, it goes back to both houses where a two-thirds majority is required to override the presidential veto.

A bill must pass both the House of Representatives and the Senate with identical language before it can be sent to the President. If there are differences in language between the two versions, a conference committee with members from both houses is established to reach agreement on the language. This situation occurs rather often, and the status of the bill at this time is that of being in "conference" or in "conference committee." When an agreement is reached, the conferees from each house take the final working back for approval by their respective committees and by the full house. If approved by both houses, it is sent on for the President's signature.

Usually, the laws that are passed by Congress contain very broad and general concepts. The language is such that the particulars of the bill are not spelled out. It is up to the agency that is going to administer the law to pass specific regulations ("regs") to cover the intent of the law. Thus, each agency has regulations writers who perform this function. These regulations become as important as the law itself and they can be found in the publication known as the *Federal Register*.

*(First paragraph) adapted from: *The Legislative Process in New Jersey*, a brochure prepared by the Office of Legislative Services, Office of Public Information, State House Annex, Trenton, NJ 08625.

**Prepared by and reprinted with the permission of: the Office of Legislative Services, Office of Public Information, State House Annex, Trenton, NJ 08627

***Prepared by: Roger Woods, Washington Office, Presbyterian Church (U.S.A.), Basic Information For Educators on Influencing Lawmakers.

GENERAL KEYS TO EFFECTIVE LEGISLATIVE ADVOCACY*

- Be knowledgeable about the legislative process at all levels (local, state, and federal).
- Know who the key decision makers are and establish yourself with their office as a respected source of information on issues related to severe handicaps.
- Keep up with current legislation that has an impact on persons with severe handicaps.
- Remain informed on the needs for changes in policy and share these needs with your legislators at appropriate times.
- Work with other advocates to identify issues on which you wish to work and establish a plan of action for these issues.
- Clearly define your position and be prepared to defend it.
- Determine who needs to be contacted, who will make the contacts, and when the contacts should be made for the maximum impact.
- Keep your strategy simple and well organized.
- Prepare written materials to accompany any personal contacts.
- In the development of strategy, don't forget the power of the media.
- Establish a strong local group of advocates and a network for quick communication.

Public Funding is the key to providing successful programs for individuals with developmental disabilities, therefore, it is important for advocates to work closely with their legislators because they make the "initial" decisions with respect to public monies.

*Reprinted from: The D.C. Update of the May, 1986 Newsletter of the Association for Persons With Severe Handicaps (TASH).

LEGISLATIVE ACTION TIPS*

Letters

One of the most effective forms of grassroots lobbying is letter writing. Letters to Congress and the New Jersey Legislature do make a difference.

- Request that the Senator or Representative/Assemblyperson reply to you with his/her position on the specific legislation you are writing about. Always be positive and thank them for their time and efforts.
- The body of your letter should be well organized, concise and in your own words.
- Keep your letter to one page, and avoid the use of buzz words and jargon.
- ** • Identify legislation by its appropriate title and by its proper bill or public law number.
- Your address and signature should be on each letter.
- Address the letters properly, as follows:

Senators (national and state)

The Honorable [full name]:

U.S. Senate
Washington, DC 20510

New Jersey Senate
State House
Trenton, NJ 08625

(or home address)

Dear Senator [last name]:

Representatives or Members of the Assembly

The Honorable [full name]:

U.S. House of Representatives
Washington, DC 20510

General Assembly
State House
Trenton, NJ 08625

(or home address)

Dear Mr./Ms. [last name].

Public Opinion Messages

Public Opinion Messages (POM) are telegrams that:

- Western Union will send;
- can be up to 20 words exclusive of name(s) and address(es).
- can be charged to your home telephone number or pre-paid at a Western Union office; and
- cost \$5.95 each.

Post Cards

Post cards are not as effective as letters, but are more practical and economical in a number of situations. Post card messages to Congress or the New Jersey Legislature should be:

- hand written if possible, but can be pre-printed if hand written messages are not practical;
- signed by the constituent with his/her home address clearly indicated; and
- addressed properly.

Visits

Visits with the members of Congress can take place in Washington, DC, or in *home district offices*. They return to their home districts several times a year during Congressional recesses and some more often than that. Visits with state legislators can take place at their district office or some designated place in the district. In preparing for a meeting with your Senator or Representative/Assemblyperson:

- call or write and make an appointment for yourself or for a small delegation — in Washington, contact the U.S. Capitol switchboard: (202) 224-3121, and in Trenton, contact your state legislator at their district office or at the State House in Trenton;
- be prepared to meet with a staff person if the member of Congress/member of the New Jersey Legislature is not available;
- present him/her with written materials such as a letter urging support; background information; a list of supporting organizations and individuals, etc.;
- briefly summarize your position, and
- make follow-up visits to discuss changes in the legislation or to inform elected officials of additional information on the issue

*****Telephoning**

Your government representative usually has a very busy legislative schedule, and he/she may be out of the office when you telephone. State the reason for the call, and ask if you can talk to his/her administrative assistant or another staffer. If it is suggested that your call be returned later, give your telephone number and indicate the general time you will be at the number. Then be there.

Your telephone conversation with your government representative or a member of his/her staff should follow the usual rules of courtesy. Be pleasant. Be brief. Tell why you are calling and be prepared to answer questions or provide related information, as succinctly and clearly as possible. Do not threaten or intimidate.

*Reprinted from: Nahigian, K. (1985). NSAC Action #1. Washington, DC.

**Added by the Autism Outreach Project.

***Adapted from: Weintraub, F.; Abeson, A., Ballard, J., & LaVor, M. (1976). *Public Policy and the Education of Exceptional Children*. (p. 290). Reston, VA: Council for Exceptional Children.

Editor's Note: Information regarding New Jersey Legislative Action Tips added by the Autism Outreach Project.

LEGISLATIVE INFORMATION - CONTACT POINTS

State Legislative Information

For further information about legislative activities at the state level, call or write your legislator at either their district office or their office in Trenton. (See *Legislative Action Tips* for the address.) The Legislature also maintains a toll free number (800-792-8630) to provide the public with information about legislative activities (status of bills, legislative procedures, calendars of events, etc.).

Federal Legislative Information

For further information about the legislative activities at the federal level, call or write to your congressperson at their Washington office. (See *Legislative Action Tips* for the address.) You may also call the Capitol switchboard for direct connection to all offices of the members of Congress and to committees (202) 224-3121. Also, you may obtain Federal Legislative Information from: U.S. Office of Education, Donohoe Building, 400-6th St., S.W., Washington, DC 20202. You may also call the following key numbers for other information:

- Ordering a House bill or committee report - (202) 224-3456
- Ordering a Senate bill or committee report - (202) 224-7860
- Status of bills in the Senate - (202) 224-2971
- Status of bills in the House of Representatives - (202) 225-1772

State Rules/Regulations

Write or call: The Office of Administrative Law, Publications Section, 9 Quaker Bridge Plaza, CN-049, Trenton, NJ 08625, (609) 588-6601. You may also request copies of the State Educational Rules/Regulations from your local school district or branch of Special Education and Pupil Personnel Services, Department of Education, 225 West State Street, Trenton, NJ 08625.

Federal Rules/Regulations

Write or call: The Federal Information Center, 26 Federal Plaza, New York, NY 10278, (201) 645-3600 or write to: Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402

To obtain an up-to-date listing of the members of the NJ Legislature and the NJ members of the U.S. Congress, request a copy of:

The New Jersey Citizen Handbook and Calendar

published annually by:

The League of Women Voters of New Jersey, Education Fund

204 West State Street

Trenton, NJ 08608

(609) 394-3303

(800) 792-VOTE

(This booklet also includes information on: voting, political parties, county and municipal governments, and the New Jersey courts.)

DATA SHEET FOR PARENTS

To Be Filled In By You

SERVICE PROVISION INFORMATION

School District: _____

School District Superintendent of Special Services: _____

County Supervisor of Child Study: _____

Regional Manager, Bureau of Programs and Services, New Jersey Department of Education:

Child Study Team Members:

_____ Psychologist

_____ Learning Disabilities Teacher-Consultant

_____ Social Worker

_____ Speech-Language Therapist

Division of Youth and Family Services (DYFS):

District Office _____

Case Worker _____

Division of Developmental Disabilities (DDD):

Regional Office _____

Intake Worker _____

Case Manager _____

Division of Vocational Rehabilitation Services (DVR):

Regional Office _____

Rehabilitation Counselor _____

LEGISLATIVE INFORMATION

State:

District Senator _____

District Assemblypersons

#1 _____ #2 _____

Federal:

State Senators

#1 _____ #2 _____

Congressional District Representative

BRIEF READING LIST

- #127 Unraveling The Special Education Maze. Cutler. \$9.95
- #147 A New Look at Guardianship: Protective Services That Support Personalized Living. Apolloni/Cooke \$24.95

Available From:

NSAC Bookstore
1234 Massachusetts Avenue, NW
Suite 1017
Washington, DC 20005
(202) 783-0125

How To Get Services By Being Assertive. Des Jardins.
\$4.00

How To Organize an Effective Parent/Advocacy Group and
Move Bureaucracies. Des Jardins. \$4.00

Available From:

Coordinating Council for
Handicapped Children
407 South Dearborn
Chicago, IL 60605
(312) 939-3513

Special Rights for Special Children: A Manual for Parents of
Handicapped Children in New Jersey Prepared by staff
attorneys. \$2.50

Available From:

Education Law Center, Inc.
Room 209
155 Washington Street
Newark, NJ 07102
(201) 624-1815

94-142 and 504: Nurabers that Add Up to Educational Rights for Handicapped Children. A Guide for Parents and Advocates. Dinsmore/Yohalem. \$4.75

Available From:

Children's Defense Fund
122 C Street, NW
Washington, DC 20001
(202) 628-8787
(800) 424-9602

Other Sources:

- Myers, J. Jensen, W., & McMahon, W. (1986). *Legal and Educational Issues Affecting Autistic Children*. Springfield, IL: C C. Thomas.
- Shore, K. (1986). *The Special Education Handbook: A Comprehensive Guide For Parents and Educators*. New York, NY: Teachers College Press.

12 Month Education for Your Child

Autism Outreach Project

Requesting An Extended School Year Program

Suggested Steps

- At your child's IEP meeting scheduled each year, request that a 12 month educational program be included in the IEP. Do not sign IEP unless it includes the components you feel your child needs.

or

- Contact the Child Study Team (CST) requesting an appointment to open your child's IEP. This can be done at any time during the school year. In this letter state your purpose. Forward a copy to your child's placement and to the superintendent of your school district.
- If your CST doesn't provide you with an appointment within a reasonable time frame, write a letter to the CST county supervisor stating your intent and the lack of timely response from your CST. Forward a copy of this letter to the superintendent of the school district and your CST.
- In order to obtain funding, your CST will recommend that the Board of Education authorize an extended school year. In most cases, the Board of Education honors the recommendations of the CST.
- If your CST refuses to make a recommendation to the Board of Education, you may petition the school board, for the decision is ultimately in their hands.

Helpful Hints:

- Do your home work! Know why your child needs an extended school year. Know the specific benefits he or she will experience.
- Obtain Documentation! Request letters or data from professionals who know your child supporting your claim that significant regression will result if his or her education is interrupted.
- Know your rights! Be well informed.
- Start early in the School year. February or March is a good time to begin. Requesting an extended program in May or June can be difficult due to time constraints.
- Make all contacts by type written, dated letters. Retain copies of everything. Do your follow-up work with telephone calls.
- Remember, any disagreement is between you and your school district. Your child's placement can provide evidence to help support your case but you, the parent, are the most effective advocate for your child.
- You must be persistent!

If you disagree with your school district's decision, the following conflict resolutions efforts can be taken:

- 1) A MEDIATION CONFERENCE can be requested through the county supervisor of Child Study Teams. Someone will listen to both sides and explore the options in efforts to bring about resolution prior to filing for a hearing.
- You have the right to appeal the decision of your school district by requesting a Due Process Hearing. Prior to making this request, it is advisable to contact the Department of the Public Advocate for assistance.
- 1) A SETTLEMENT CONFERENCE, the first step in Due Process, is conducted by a settlement officer who will mediate the discussion between you and your school district and suggest a solution. If an agreement is reached, it is documented and signed at that time.
- 2) A DUE PROCESS HEARING is conducted by an Administrative Law Judge. It is helpful to have a lawyer represent you since, in most cases, your school district will have a lawyer present. A Due Process Hearing can be requested by writing to the Director of the Division of Special Education.

If you have any questions or are in need of assistance in your advocacy efforts, contact:

Why . . . ?

An extended school year program is an important part of the education of many children with developmental disabilities. These children sometimes experience what has been called "the regression/recoupment cycle". This means that a child "regresses" during time spent away from his or her educational program and must then spend weeks and even months "recouping" or regaining the skills and behaviors he or she once had learned. This is especially true of children who have autism. In order to help prevent this cycle, your child may need a full year educational program that extends through the summer months. This insures that your child IEP is uninterrupted. You and your child study team will need to include this vital component in your child's IEP.

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