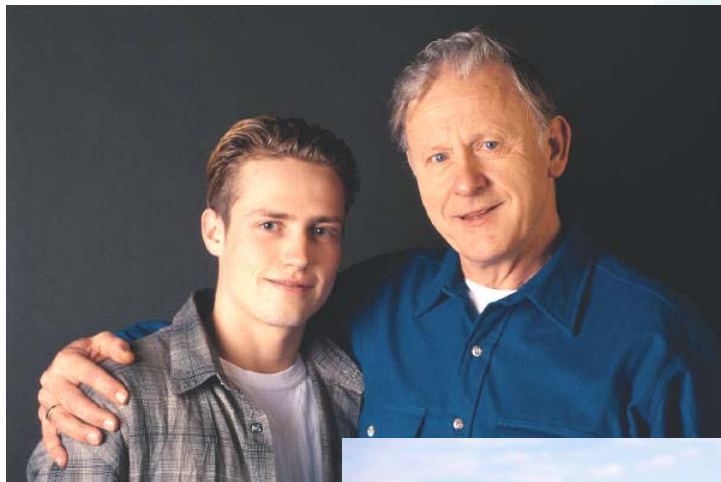


NAVIGATING THE MENTAL HEALTH AND EDUCATION SYSTEMS

A CAREGIVER'S GUIDE



Courtesy of NAMI Southwestern Pennsylvania
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Introduction

Parents are often the first persons to suspect something may not be quite right with their child's behaviors. Perhaps they cannot pinpoint the specific cause of their concern, but they are concerned nonetheless. NAMI Southwestern Pennsylvania has developed this Caregiver's Guide as an introductory resource for parents and caregivers to use to assist them in navigating the seemingly complex and often still fragmented mental health and public education systems.

Early identification and treatment of mental illness or serious emotional disturbance is of vital importance; when children and adolescents can access the treatment they need early, research has shown that recovery is accelerated and the course of illness may be less severe.

Acquiring needed information and education is essential to a parent's ability to effectively advocate for their child's behavioral healthcare and required educational supports. This booklet notes the warning signs that may indicate the presence of a mental illness or serious emotional disturbance, includes information on choosing a mental health treatment professional, and provides an overview of available children and adolescence mental health treatment and supports. As parents often cite concerns with the public school system, we have included chapters on education rights and tips for development of effective education plans.

The resources noted in the back of this booklet include contact information for organizations that offer additional support and information that families need to understand their child's illness, the mental health system, or the school system.

NAMI Southwestern Pennsylvania is a regional grassroots non-profit organization of families and individuals whose lives have been affected by mental illness. We advocate for lives of quality and respect, without discrimination, for all of our constituents. We provide leadership in advocacy, policy development, education, communication, and support.

Our membership is diverse—families and caregivers of children and adolescents with serious emotional disturbances; adults whose parent, sibling, partner, or adult child has a mental illness; consumers of mental health services; mental health professionals; and others who believe in our cause.

We embrace young families, parents and caregivers of children and adolescents with a mental illness or serious emotional disturbance through providing monthly support meetings, telephone outreach, education programs, fact sheets on mental illness, available treatments and supports, and a quarterly newsletter highlighting issues of concern to the mental health community.

If you share our belief that individuals with a mental illness deserve a chance at a better life, help us advance our efforts by becoming a member. For more information on NAMI's services and supports, contact us today at 1-888-264-7972 or info@namiswpa.org.

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Section 1: When Should I Be Concerned About my Child's Behavior?

Parents, even if they are not aware of the developmental milestones of child development, can sense when something is wrong with their child. Often, this is realized by comparing their child to other children of the same age. Family members may gingerly bring up the subject, but often parents do not want to hear the opinions of others and will deny that a problem exists. They often quote their pediatrician who says there is nothing to worry about even though there is a gnawing feeling that something is not right. Parents need to be aware of the warning signs that something is amiss. The following are warning signs that may indicate a problem.

Children of Elementary School Age

- Unusual sleep patterns, sleeping too long or not being able to fall asleep.
- Refuses to go to school regularly or attend social functions; losing interest in things once enjoyed.
- Isolation from friends and family.
- Expresses anxious thoughts, constantly worried, or fearful more than others his/her age.
- Frequent temper tantrums for no apparent reason.
- Over concern about physical concerns or physical appearance.
- Frequent intense nightmares.
- Attending school regularly, doing homework, but still getting bad grades.
- Child never slows down, often exhausting and demanding or can appear to be oblivious to the world around him/her.
- Is disorganized, can only concentrate for a very short time, attention is minimal.
- Frequent opposition to authority figures (parents, teachers, etc.) and a lack of remorse for bad behavior.
- Is fine in school but shows unusual behaviors at home; seems to “put on a good face” when he is out of the house.
- Feels the need to stay in rigid routine; repeatedly washes hands or insists on cleaning constantly.
- Does not seem to understand social norms; cannot make friends or understand the feelings or behavior of others his/her age.

Pre-teens and Adolescents

- Isolation from friends and family.
- Intense fear of becoming obese despite normal body weight; poor self image; constantly dieting, eats very little or purges food (vomiting).
- Opposition to authority figures that often leads to truancy, breaking the law, or assaulting others.
- Addictive behaviors—abuse of alcohol and/or drugs or tobacco products.

- Promiscuous behavior—sexually acting out.
- Excessive use of the computer on chat lines.
- Prolonged negative mood, poor appetite, sleep difficulties (too little or too much) thoughts of death.
- Cutting body but not in act of suicide.
- Expresses strange thoughts, unusual feelings; hearing voices.

It is always wise to discuss your concerns with professionals who work with your child—day care workers, teachers, after school program teachers, etc. so that you are knowledgeable about your child’s behavior throughout the day. Be aware that children do not often display the behaviors you see at home in public places. Children sometimes “hold it together” in public places (school, community settings) and then display aggression, anger, sadness, at home where they feel safe and out of public scrutiny. Parents often blame themselves when this occurs; but in school or other public places, children have more structure and more peer pressure to enforce “typical” behavior even though the stress of being “typical” is very demanding when the child is experiencing severe anxiety, depression, mood swing, or obsessive behavior. When the child returns home, he or she can no longer prolong this charade so the behaviors return full force.

If your doctor or pediatrician insists there is nothing wrong and you feel there is, feel free to get a second opinion from a psychiatrist, neurologist, or psychologist. You really have nothing to lose. If all is well, then your physician was right. If not, you can work toward getting your child/teen the help he/she needs.

Section 2: My Child Needs Help - Who Do I Call?

Parents can choose different routes in the mental health system to obtain services for children/teens. If you choose to get a full evaluation from the start, you may want to call for an appointment with a Child Psychiatrist or Psychologist.

Parents can also choose to contact a Service Coordination Unit for services for their child. A thorough explanation of this agency will be explained in Section Five of this handbook.

If you think your child needs to begin with therapy sessions, you may need to investigate child therapists in your area. If your child is young (5-10), do not be surprised if the therapist does “play therapy” with your child. Children do not readily talk about their problems or feelings. This type of therapy may appear as if they are “just playing,” but a play therapy session with a trained therapist can be very beneficial to a child with emotional problems. Sometimes, therapists will send a child for a Psychiatric evaluation if they feel that medication would help the child along with therapeutic sessions.

Another option is to contact a nearby hospital that has a Child/Adolescent Unit that evaluates children for emotional and/or developmental problems. Check to make sure that a child psychiatrist will be participating in the evaluation process.

The following information will assist you in finding the professional you feel will be the best for your child:

Child and Adolescent Psychiatrist – A child and adolescent psychiatrist is a licensed physician (M.D. or D.O.) and a fully trained psychiatrist with two additional years of advanced training that concentrates on children, adolescents, and families. For the most part, they provide psychiatric evaluations for behavior problems and psychiatric disorders. They can also prescribe and monitor medications.

Psychologist – Psychologists can have a master’s degree (M.A. or M.S.) in psychology while others have a doctoral degree (Ph.D., Psy.D. or Ed.D.) in clinical, educational, counseling, or research psychology. They can provide psychological evaluations and treatment for emotional and behavioral disorders. During the evaluation process, they often do psychological testing and assessments. School Psychologists usually have a master’s degree acquired through a school or university’s school of education. Among other duties, they are responsible for evaluations that are done in school settings. In order to get an evaluation in the school setting, parents must request that an evaluation be done and also give permission to have the evaluation done. **This request must be in writing.**

Social Worker – Social workers can have a bachelor’s level degree (B.A., B.S.W. or B.S.) Social workers who have master’s degrees (M.A., M.S., or M.S.W.) usually are licensed in their state (L.S.W.) and can provide most forms of psychotherapy.

How do I determine if there will be a good “fit” between my child and the treatment professional?

It is wise to choose a treatment professional that is easily accessible via driving distance or public transportation. It is important that the treatment professional work during times you and your child are available (evenings, weekends). These are the questions you may wish to ask the treatment professional you are considering for your child:

- Have you worked with children that have the diagnosis of your child?
- How do you feel about a child taking behavioral health medication?
- What will happen in your sessions with my child? (Especially if the child is too young for “talk” therapy)
- How much will you tell me about what goes on in a therapy session?
- Have you worked with children who are hesitant to go to therapy or think they do not need therapy?
- Will you work with my child and also his/her family members so that they can assist the child to work on behavior issues?

It is important that the child feel comfortable with the treatment professional. If after a few sessions you feel your child is not comfortable, feel free to discuss this issue with the treatment professional working with your child. A professional will not be offended and should be willing to discuss this problem with you. If not, you can find another individual who meets your child’s needs.

Section 3: Who Will Pay for the Expensive Treatment my Child Needs?

If you have private insurance, you must contact your provider (the number for behavioral health will be on the back of your insurance card) and request a list of mental health professionals in your area that are covered by your insurance plan. You can also discuss with your provider how to obtain an evaluation and the number of visits that your insurance will cover.

If your child has medical assistance (MA), you will have access to many programs that private insurance will not cover. To ascertain how to access these services, please contact NAMI Southwestern Pennsylvania at 1-888-264-7972 or go to our website www.namiswa.org.

How can I get Medical Assistance for my son/daughter?

To understand eligibility requirements, read the following information from The Pennsylvania Health Law Project. Pennsylvanians can apply for Medical Assistance online at the Pennsylvania Department of Public Welfare website: www.dpw.state.pa.us.

What is HealthChoices?

HealthChoices is Pennsylvania's managed care program for adults and children on Medical Assistance. This program includes both physical and behavioral health care. Adults and children who receive the following types of Medical Assistance can participate in the HealthChoices program:

- Temporary Assistance to Needy Families (TANF)
- Healthy Beginnings
- Healthy Horizons
- Supplemental Security (SSI) including:
 - SSI with Medicare
 - SSI without Medicare
 - SSI –related
- General Assistance (both State-only and federally-assisted Medical Assistance)

HealthChoices offers mental and substance abuse services as the program's behavioral health benefits. Services available to individuals enrolled in the HealthChoices Program include:

- Hospital based services
- Behavioral Health Rehabilitation Services for Children and Adolescents (BHRS)
- Emergency Services
- Community Based Outpatient Services

Getting Medical Assistance for a Child (under 21) with a Severe Disability, Mental Illness or Behavioral Disorder under the “loophole”

Why Medical Assistance?

Medical Assistance has the broadest coverage of medical and mental health services for persons under 21 of any insurance plan. It covers services rarely covered by employer provided insurance such as mental health wraparound services, shift nursing (8 hours or more per day), in-home personal care services, diapers, nutritional supplements, prescriptions and transportation to and from medical appointments. It also covers services, like in-home nursing, physical, speech or occupational therapy, without annual or lifetime caps often imposed by other insurance plans. Medical Assistance can be a child’s only insurance or it can be a secondary to other coverage, covering those services or equipment not covered by the child’s primary insurance.

Will my Child Qualify?

There is a common misconception that all children with a disability or all children with an IEP (Individual Education Plan) or all children with a particular diagnosis qualify for Medical Assistance. That is not the case. The rules are just not that simple. However, many children with severe disabilities will qualify for Medical Assistance regardless of their parent’s income. Here are some basic rules:

- A child can qualify for Medical Assistance even if she or he has other health insurance (although the other insurance usually needs to be billed first).
- The assets of the parent(s), guardians, and the child (money in the bank, stocks, bonds, etc.) don’t count in determining eligibility for Medical Assistance.
- The income of caregivers and guardians other than the parents don’t count.
- The income of the parent(s) doesn’t count if the child’s condition meets certain disability standards.

This guide will try to explain the rules that apply to children with severe disabilities, mental illness, or behavioral disorders.

Note: This guide does not deal with the eligibility for Medical Assistance of children who are in foster care or otherwise in custody of a county children and youth agency.

Eligibility Requirements for Category PH95, a.k.a. “loophole”

- **Age:** Under 21. However, many children who had been on Medical Assistance under this category will qualify for SSI when they turn 18 because at that age, parental income is no longer counted for SSI eligibility.
- **Disability:** Child must meet the Social Security disability guidelines (more about that later).
- **Resources (assets):** Not considered (neither the parent’s nor the child’s).
- **Income:** Income of the parents or other caregivers is **NOT** counted. However, income that is legally considered to be the child’s **IS** counted. The more common types of income which is counted (because they are considered to be the child’s) are listed below. Having countable income does not disqualify a child from Medical Assistance, so long as the amount of the income does not exceed the

income maximum. The maximum amount of countable income a child with severe disabilities can have and still get Medical Assistance is \$748 a month for the year 2003 (it goes up some each year).

What income is counted:

- **Social Security:** "Child's benefits" or "survivors benefits" (not SSI) which are based on the past earnings of a deceased or disabled parent. Often, the surviving or custodial parent will get one check for him/herself and another in the parent's name for the child (both names are on the check). It is the check in the parent's name for the child that is counted;
- **Railroad Retirement Benefits:** The Child's share (the check in the parent's name for the child) is counted;
- **Interest or Dividends:** on bank accounts, stocks, bonds, CDs or other investments that are in the child's name (reported to the IRS under the child's Social Security number). The principal (the amount on which the interest or dividend is paid) is not counted (it's considered a resource that is exempt).
- **Earnings from Child's Job:** If the child is working, a portion of those earnings is counted. However, a child that earns enough to be over the income limit would probably not qualify for Medical Assistance under this category anyway because they probably would not meet the disability guidelines. Call the Health Law Project for more information if the child is employed at 1-800-274-3258.
- **Trust Funds:** The rules about how trust funds affect Medical Assistance eligibility depend on how the trust is set up and are too complex to set out here.

What income is not counted:

- **Court Ordered Child Support:** Medical Assistance used to count child support payments on the grounds that child support was legally income to the child, not the parent (and only parental income is disregarded under the loophole). However, effective September 1, 2000, Medical Assistance no longer counts child support for children who meet the disability standards provided the support is court ordered (it remains counted for non-disabled children). This change is documented in Operations Memorandum 000-806 revised 09-01-00 issued 8-31-2000 effective 9-1-00.

The Application Process for Category PH 95 (loophole)

Application is made at the County Assistance Office in the county where the child resides.

1. Get an SSI Eligibility Determination

SSI (Supplemental Security Income) is a program administered by Social Security that provides a monthly check and Medical Assistance to persons who meet Social Security's disability criteria and have low incomes and assets. Even if the family is not seeking SSI, screening for eligibility for SSI is required by state regulations (55 PA Code §141.21(n)(2)) when Medical Assistance is sought for a child under the PH 95 (loophole) category if the child is potentially eligible for SSI due to disability or medical condition. Unlike Medical Assistance, under the loophole parental (and stepparent) income and assets **DO** count in determining eligibility for SSI. However, Medical Assistance will not be denied if parental income or assets exceed the SSI limits. Therefore, it is sufficient to get a denial for SSI from Social Security so long as the denial is on the basis of income or assets not because Social Security has determined the child does not meet their disability requirements. The SSI eligibility screening can be done with a simple phone call in most cases. To get a determination as to whether the child meets the income and resource requirements, you should do the following:

- Call Social Security at 1-800-772-1213. When you hear the recorded message, press 0 then, when the next message comes on, press 1. You will get a live Social Security representative. The parent/guardian should ask the Social Security representative that they would like to have an appointment set up for an SSI eligibility screening over the phone. The representative will give

you a date and time when a representative from your local Social Security office will call to take the necessary information.

- Remember that parent's and stepparent's income and assets count for SSI so be sure to have pay stubs, bank statements, and other income and resource records available on the date Social Security calls back.
- If the Social Security representative determines that the parent/stepparent/child's income or resources are over the SSI limits, ask the representative to send a written letter to that effect. Keep that letter to submit to the County Assistance Office as proof that the child was denied SSI.

If the child had been on SSI recently (in the last year or so) and was terminated due to parental income or resources of the parent(s) or child, the County Assistance Office will usually accept the fact that the child had been on SSI as proof the child meets the Social Security disability standards so long as the child was not terminated on grounds that he/she was no longer disabled.

Tip: If the child was terminated on the grounds that he/she no longer met the disability standards, it is essential that the parent/guardian appeal the SSI termination (they have 65 days from the date on the SSI termination notice to do so). Otherwise, the determination of Social Security that the child does not meet the disability standards will be binding on Medical Assistance and the child will not qualify under category PH 95.

What if I call Social Security and find that my child qualifies for SSI?

In some cases, the parent/stepparent/child's income is within the SSI limits. In that case, the parent will have to file a full SSI application at their local Social Security office and Social Security will determine whether the child meets the disability guidelines. To find the closest Social Security Office, call 1-800-772-1213 or go to <http://www.socialsecurity.gov/onlineservices> on the web. See the section before on SSI. Note that if Social Security determines that the child does not meet the disability guidelines, the child will not be eligible for either SSI or for Medical Assistance under the PH 95 (loophole) category although the child may be eligible under a different category of Medical Assistance, like Healthy Beginnings, where disability is not a requirement but parental income is counted. Therefore, if the child is found not to meet the SSI disability guidelines and does not qualify for Medical Assistance under one of the "non-disabled" categories, it is critical that the parent/guardian appeal Social Security's decision.

2. Get an Application Form

Two application forms are available—the PA600 (long form) and PA600CH ("Application for Health Care Coverage"). It is strongly recommended that the parent/guardian use the PA600CH form. You can obtain the form by calling 1-800-986-5437. You can also download the application form from the web at <http://www.dpw.state.pa.us>. To print out the application off the web you will need Adobe Acrobat reader, which is free. Go to <http://www.adobe.com/products/acrobat/readstep2.html> to download this extremely useful application.

3. Fill out the Application Form

For the PA600CH, start on page 3. The parent/guardian puts his/her name in Part I on page 3 (at bottom).

- Page 4: On the top line of the 4th page (part II), put the parent/caregiver's name. On the same top line, check the NO box in the column "Are you Applying for this Person." On line 2 ("Person 2"), list the child's name for whom the application is being made and be sure to check the YES box in the column, "Are you Applying for this Person" on the line where the child's name is. If you are applying for more than one child, list the other child(ren) on the following lines. Information about a stepparent is also requested. If the child for whom you are applying has a stepparent at home, put in the stepparent's name at the bottom of the page (after "Are you, or is anyone who lives with you, a stepparent?").
- Page 5: The top of Page 5 asks for income by source (part III). Under a new state law, income of the parent(s) must be listed here—even though it is NOT counted in determining the eligibility

of the child (provided the child meets the disability requirements). Income of stepparents need not be reported.

- Put in the amount of Social Security or child support (if any) received for the child for whom the application is being made in the applicable box and put the child's name in the box, "Whose income is this?". Remember that court-ordered child support will not affect the child's eligibility. If there are any bank accounts or other investments listed under the child's name or reported to the IRS under the child's Social Security number, report the interest or dividend that has accrued and the time period during which it has accrued (monthly, quarterly, annually?) in the "Dividends/Interest" box. The questions about how much the parent/guardian pays for childcare and for travel to work are not relevant to eligibility under category PH95 (loophole).
- Page 6: You do not need to list other insurance (part IV) under which your child is covered as well as your care insurance policy (if any). Having other coverage does not disqualify a child for Medical Assistance, but it does affect how Medical Assistance pays for services.
- Page 7: Be sure to fill out "Health Insurance from Your Employer." Under certain circumstances, a special Medical Assistance program called "HIPP" can pay the premium your employer charges to have your child covered under your health insurance at work and can even pay to have you covered as well! Special Qualifying Information—Make sure to check YES next to the question, "Do you or does anyone who lives with you have a disability or a special health care need?" Then fill in the child's name below that. If you have unpaid medical bills for services from the past three months and the provider to whom you owe the bill accepts Medical Assistance, you should check the "yes" box.
- Pages 8-9: The questions on pages 8 & 9 are optional.
- Page 10: Be sure to sign twice on page 10—1) right above "Certification of Citizenship or Alien Status" where it says "Signature of Applicant" and 2) at the bottom of the "Certification of Citizenship or Alien Status" block where it says, "Sign here."

4. **Get the Child's Birth Certificate**

To obtain an official copy of a birth certificate for a child born in Pennsylvania, call 724-656-3100 or go to <http://www.health.state.pa.us?HPA/birth.htm> on the web.

5. **Get the Child's Social Security Card**

If the child doesn't have one or needs a replacement, get an application for a card from the local Social Security office (form SS-5). Call 1-800-772-1213 or the TTY number 1-800-325-0778 for more information or go to http://www.ssa.gov/replace_sscard.html on the web.

6. **Assemble Documentation of the Child's Disability or Condition**

While Social Security will do this for families applying for SSI, it is the parent/guardian's responsibility to do this when applying for Medical Assistance under the disabled child (loophole) provision. Remember that unless the child is found to meet the disability standards, the income of the parent/guardian will be counted. The people who make the disability determinations will not examine or evaluate the child. If the problem or limitation is not documented, it will not be considered.

7. **The Disability Standard (What You Need to Document)**

It is not enough for a child to have a disability, a specific diagnosis or an IEP in order to qualify for Medical Assistance under SSI or the non-SSI disabled child (loophole) provision. The child's disability or condition must meet a set of standards. The standards used, even for children applying just for Medical Assistance under the loophole, are the Social Security childhood disability standards. Those standards are called the "Childhood Listings of Impairments." They can be found on the web at http://www.ssa.gov/OP_Home/cfr20/404/404-ap09.htm (scroll down to Part B, section 100.00, which is where the listings for children begin). The standards vary depending on the "body system" that is affected by the disability or condition. You will need to find the body system that is affected by your child's disability/condition to determine which of the standards apply.

However, as a general rule of thumb, the disability standards consider the extent to which the child's disability/condition limits the child's ability to perform basic functions (appropriate for his/her age

group). These basic functions include physical and neurological functioning (ability to walk, talk, feed oneself, etc.), sensory functioning (ability to see or hear), cognitive functioning (ability to learn and understand) and psychological functioning (ability to develop and maintain relationships with others, avoid violent behavior and dangerous situations, etc.).

A parent/guardian should not try to determine whether their child's condition meets the listings. The usefulness of the listings to parents is to determine what they will need to document. In most cases, it is necessary to document the nature, severity, frequency and duration of the limitation(s) in addition to the medical or psychiatric condition that causes the limitation(s). Important sources of documentation include: the child's doctors, therapists, teachers, guidance counselors and school records (including the Comprehensive Evaluation Report, the Multidisciplinary Evaluation or "MDE," report cards and attendance records). IEPs are not enough because they focus on educational issues that are not the primary focus of the Social Security disability standards. For more information regarding the "Listings of Impairments" that apply to children with mental illnesses or bio-neurological conditions, ask us for the guide on that topic.

8. Filing the Application

The application needs to be filed at your local County Assistance Office. You can find the location and phone number of your County Assistance Office in the blue pages of the phone directory under "Government & Other Public Services—Public Welfare" or on the web at <http://www.dpw.state.pa.us>. The application can be filed by mailing it or by taking it to the County Assistance Office in person. If mailing, send it certified or get a mailing certificate to prove when you mailed it. If you are dropping it off at the County Assistance Office, ask for a receipt.

Two Options if Filing by Mail

- a. Send in only the application form. This will usually result in getting a call or notice from the County Assistance Office to schedule an "intake" appointment at the County Assistance Office. Sometimes a worker from the County Assistance Office will conduct a "screening interview" over the phone. NOTE: If, during the screening interview, the worker indicates that the child is not eligible, the parent/guardian should insist that the application process be completed or else he/she may have waived their appeal rights. At the intake appointment, the parent/guardian must bring in the necessary documentation (see below).
- b. Request that the intake appointment be waived. Under this option, the application is processed based on the documents submitted, without the need to go into the County Assistance Office. In order to do this, the parent/guardian needs to submit a completed and signed application form along with all necessary documentation (see below).

The application and documentation should include a cover letter with the following sentence: **"I am requesting that the face-to-face interview be waived pursuant to Medical Assistance Eligibility Handbook sections 304.4 and 378.3. Please contact me at (daytime phone #) if additional information or documentation is needed."**

Filing in Person at the County Assistance Office

This is usually the quickest way although the least convenient. Some County Assistance Offices take people on a first-come first-served basis so it is possible, if you can wait long enough, to have the application process completed in one day, provided you have all the necessary documentation.

Necessary Documentation

- The child's Social Security card (or receipt from Social Security that an application for a card has been filed).
- The child's birth certificate (original or state-certified copy—not a photocopy) or some acceptable alternative.
- Proof of immigration status for non-citizens.
- Some proof of address (usually the parent/guardian's drivers license if the address is current).

- Documentation of income in the child's name (Social Security notices or photocopies of checks, child support orders or statements from Domestic Relations, bank statements or other statements showing interest, dividends or other earnings on bank accounts or other investments in the child's name)
- Documentation of the nature and extent of the child's disability or condition or, for a child recently on SSI, an SSI termination notice, if the grounds for termination were excess income or resources, not lack of disability.
- Documentation that the child does not qualify for SSI letter from Social Security).
- Health insurance policy numbers (or a copy of the card if available) or any insurance under which the child is covered.
- Car insurance policy number (if the parent[s] have a car). This is needed because car insurance often provides coverage of health care expenses related to an automobile accident.

Documentation that is NOT Necessary

- Documentation of resources (real estate, cars, life insurance policies, bank accounts or other investments not in the child's name.

What to do if the Caseworker at the County Assistance Office Asks about Assets (Parents' or Child's)

1. As to requests for information about parent's assets (cars, real estate, bank accounts, stocks, bonds, life insurance), refer the caseworker to section 340.1 of the Medical Assistance Eligibility Manual, which states: "There is no resource determination for individuals in an applicant/recipient group if the individual is a child under age 21...". Since "there is no resource determination," there is no need to provide information about the parent's resources or assets.
2. As to requests for information about assets in the child's name, remember that the parent or guardian must provide documentation about any interest, dividends or other earnings on bank accounts, stocks, bonds, CDs or other investments which are in the child's name (reported to the IRS under the child's Social Security number). These are considered income and are counted in determining the child's eligibility. However, it is only the interest, dividends or other earnings that can be counted. Therefore, even though the parent or guardian must provide documentation about the account or investment to document the amount of income earned in the child's name, the market value of the bank account, stocks bonds or other investments does not affect the child's eligibility. If the caseworker says otherwise, refer her/him to section 340.1 of the Medical Assistance Eligibility Handbook.

What to do if the Caseworker Tries to Deny Medical Assistance for a Child with Severe Disabilities Based on Parental Income

1. Tell him/her that parental income does not count for Medical Assistance under Category PH 95 and refer him to the description of "program status code 95" in the MA Eligibility Handbook section 305 Appendix C-6 which states, "A child under age 18 who is disabled and whose parental income is not considered in the financial determination of MA eligibility."
2. Also refer the caseworker to section 355.4 of the MA Eligibility Handbook which states, "There are no provisions to deem income from a parent to a child who is receiving PJ or TJ. (PJ and TJ are categories of Medical Assistance based on disability.)"
3. Also refer the caseworker to Medical Assistance Eligibility Handbook section 319.3 which states, "There are no provisions to require consideration of income from a parent to a child receiving Healthy Horizons" (the category of Medical Assistance for persons determined disabled who do not qualify for SSI).

Authorization to Release Information – Form PA 4

Caseworkers will usually insist the parent/caregiver sign a blanket release form which allows DPW to contact employers, banks, etc. to obtain financial information relevant to the child's application for Medical Assistance. State regulations require a parent/caregiver to sign this release form in regards to "information about...the applicant or recipient..." (55 PA Code §201.4[1][ii]). State regulations state that "the applicant" includes "The adult with whom an unemancipated minor lives..." (55 PA Code §123.82). Therefore, the parent/caregiver is legally obligated to sign the PA 4 form to release information regarding both the child and the parent, even though parental income and assets are not relevant. Of course this is a conflict in the law since the Medical Assistance Eligibility Handbook says parental income and resources don't count. Unfortunately, the requirements to sign the PA 4 are in regulations while the "loophole" provisions are only in the Handbook and the regulations take precedence over the Handbook.

What Happens Next for Medical Assistance?

Determining Disability

Once the application and necessary documentation has been submitted, the caseworker at the County Assistance Office has authority to immediately find that the child meets the disability standards, pending a final decision by the Medical Review Team (which takes months) if, based on the documentation provided by the parent/guardian, the child "appears to be disabled." This is authorized by Medical Assistance Eligibility Handbook §305.26. This is known as "presumptive eligibility" and is very common if good documentation is provided. If the caseworker doesn't feel comfortable making the 'Presumptive eligibility' disability determination him/herself, ask the caseworker to transfer the case to the "DAP Unit" (Disability Advocacy Program Unit) at the County Assistance Office. The DAP Unit is comprised of workers specially trained in the disability standards. They will usually review the medical or psychiatric documentation and may request that the parent/guardian get additional documentation or come in for an interview.

If the caseworker or the worker from the "DAP Unit" finds the child "presumptively eligible," the caseworker can authorize Medical Assistance immediately. A Medical Assistance ID card (a.k.a. "Access Card") should arrive in one to two weeks. If the child needs services under Medical Assistance before that, the parent/caregiver should ask the caseworker for the child's Medical Assistance ID#, care issue #, category, and program status code. With those numbers, most providers are willing to start serving the child under Medical Assistance without waiting for the official ID card (know as the "Access" card). If the provider insists on an official card, the parent/caretaker can request an "Interim Medical Card" from the caseworker at the CAO. An Interim Medical Card can be done in a day. The caseworker cannot require documentation of a medical appointment. The statement of the parent/caregiver that there is an immediate need for the card is sufficient (Medical Assistance Eligibility Handbook §380.4).

Once the case has been authorized, the caseworker is supposed to transfer the case to the DAP Unit to review the medical or psychiatric documentation if they have not already done so. After that, the DAP Unit is supposed to send the documentation to an agency under contract with Medical Assistance, known as the Medical Review Team (MRT) which makes the final decision as to whether the documentation shows that the child meets the disability standards. If the MRT decides that the child's documented condition does not meet the disability standards, the County Assistance Office will terminate the child's Medical Assistance unless the child is eligible under another category. However, the parent/caregiver can appeal the MRT's decision; and if the County Assistance Office receives their appeal within 10 days of the termination notice being mailed, the termination cannot go through until after the family has had a hearing and gets a hearing decision. (Of course, if the parent/caretaker wins, the termination won't go through at all.) The termination notice explains how to appeal.

Enrollment in an HMO

Children living in the following counties will be required to enroll in an HMO that has a contract with Medical Assistance: Adams, Allegheny, Armstrong, Beaver, Berks, Bucks, Butler, Chester, Delaware, Fayette, Greene, Indiana, Lawrence, Lehigh, Montgomery, Philadelphia, Washington, and Westmoreland. This is required even if the child has other health coverage, including another HMO. The services the child needs (other than behavioral health services) are then obtained through the HMO, rather than through medical Assistance itself, although the HMO must cover all the services regular medical Assistance covers. The requirement that a child living in one of the counties listed above be enrolled in one of the Medical Assistance HMOs applies even if the parent/caregiver is only seeking coverage for behavioral health services, even though the Medical Assistance HMO does not directly provide that coverage.

For children living in the counties above, coverage for behavioral health services comes through a separate entity called a "Behavioral Health Managed Care Organization" which has a contract with the county MH/MR agency. In Philadelphia, that entity is Community Behavioral Health (CBH), in Allegheny it is Community Care Behavioral Health (CCBH). In Bucks, Chester, Delaware, Lehigh, Montgomery, and Northampton counties it is Magellan Behavioral Health. In Armstrong, Beaver, Butler, Fayette, Greene, Indiana, Lawrence, Washington and Westmoreland, it is Value Behavioral Healthcare. In Adams, Berks, and York Counties, it is Community Care Behavioral Healthcare Organization (CCBH). In Cumberland, Dauphin, Lancaster, Lebanon, and Perry Counties, it is Community Behavioral HealthCare Network of PA (CBHNP).

Medical Assistance HMOs are also in operation in several other counties besides the ones mentioned above. However, in those other counties enrollment in one of these Medical Assistance HMOs is voluntary.

4/29/03

Section 4: What are Service Coordination Units?

Children and adolescents in need of services are eligible for mental health services provided under the auspices of the county in which they reside. Need for particular services are determined by an assessment and the development of an individual service plan. Eligibility is based on meeting the requirements of “medical necessity.” Although there are many definitions of “medical necessity,” your private insurance or Medical Assistance will determine what “medical necessity” means. Generally, it is the principle of providing services which are “reasonable and necessary” or “appropriate” in light of clinical standards of practice.

Types of services that Service Coordination Units provide include case management, outpatient services, in-patient care, day treatment/partial hospitalization, residential treatment facility (RTF), emergency services, and family support. If your child has Behavioral Health Rehabilitation Services (BHRS) through Medical Assistance, you can still be eligible for services offered by the Service Coordination Unit. Fees for service can be paid by medical insurance or are based on a sliding fee schedule. The formula uses the incomes and living expenses of the individual or the responsible family member to determine how much the fee will be billed to the client. The Service Coordination Units provide services in a variety of ways. Some provide services themselves and some contract with other agencies to provide services. To apply for services through the Service Coordination Unit, you need to contact the Service Coordination Unit in your area or in any area you choose in your county. The following is a description of the services provided within this system:

Case Management: Children and adolescents diagnosed with mental illness can be involved in a number of systems. Busy parents are often not aware of all the services they can utilize to help their child/adolescent. The case manager coordinates care for the child and ensures that all the systems involved are working together to assist the family.

There are three categories of case managers: Intensive Case Manager (ICM), Resource Case Manager (RCM) and Administrative Case Manager (ACM). The level of need determines which case manager will be working with the family.

- Administrative Case Manager (ACM): Usually the first initial contact with family; assures that assessments are done, a treatment and service plan is written, referrals are made, and that the child/adolescent receives treatment and supports services.
- Resource Coordinator (RC): Needed when child/adolescent is experiencing significant mental health problems; two or more mental health providers or systems (education, child welfare, and juvenile justice) are involved with the child; the RC assists in coordinating services.
- Intensive Case Manager (ICM): Needed when child/adolescent is having difficulties with ability to function at home, school, community settings. ICM sees the child/adolescent frequently and serves as a link between multiple systems and advocates for the child in all of those systems to be sure the child/adolescent gets needed services.
- Targeted Case Management (TCM): Also known as “Blended Case Management.” Often those with mental illness need an Intensive Case Manager for a while until he/she improves and is offered the services of the Resource Coordinator. Mental illness, much

like other chronic disorders, fluctuates, so the individual will be going to the ICM for a while and then switch to a RC, going back and forth, which creates havoc for the client. Targeted Case Management allows the client to remain with the ICM even when he/she improves allowing this positive and trusting relationship to continue throughout the course of the illness. Some counties in Pennsylvania are implementing this type of case management. If you are interested in getting a Targeted Case Manager (TCM), call your local MH/MR to find out if this service is offered in your county.

Outpatient Treatment Services: Community-based services that provide evaluation/diagnosis, treatment planning, medication management, individual and play therapy.

Day Treatment/Partial Hospitalization Programs: Children/adolescents with mental illness participate in an intensive non-residential program. They commute to the program every day (hospital or community agency) for some part of the day. Sometimes, the school component is within the day treatment program. Other day treatment programs commence after school hours.

Short-Term Inpatient Services: Provides psychiatric service when children/adolescents have acute symptoms. The goal is to stabilize the symptoms so that the child can return to their home and community. Children and adolescents who are a danger to themselves or others may be mandated for a psychiatric evaluation and treatment if necessary.

Residential Treatment Facility (RTF): Children and Adolescents with severe mental illness stay in this facility as long as medically necessary. Trained staff provides services and supervision 24 hours, 7 days a week.

Section 5: What are Behavioral Health Rehabilitative Services (BHRS)?

BHRS services are available to a family if the child has a valid medical assistance card in the state of Pennsylvania. Another name for this service is wraparound services. Wraparound Services are a form of psychological treatment that takes place in the least restrictive environment (home, school, community). This atmosphere encourages the child to reach his/her full potential in a natural setting. The wraparound service provides a highly individualized service to meet the needs of the child and family. These services are to be cognizant of cultural differences and work within the framework that incorporates the strengths of family. If a child/teen meets the criteria for medical necessity, a case manager meets with the family, facilitates a discussion exploring the strengths of the family, assists the family to create reachable goals, and develops options to meet those goals.

The Behavioral Specialist Consultant (BSC) must have a Master's Degree or higher and also have experience in behavioral interventions and treatment of children with developmental delays and serious emotional disturbance. The BSC writes the treatment plan and develops the program to be implemented in the child's home, school, or other community settings.

The Mobile Therapist (MT) must have a Master's Degree and provides counseling services to the child or family.

The Therapeutic Staff Support (TSS) must have a Bachelor's Degree and works with the child in whatever environment the treatment team chooses (school, home, and community) and implements the plan developed by the BSC.

Where do I find these services?

Your Coordination Units will have information concerning providers of wraparound services. The child must have a Medical Assistance card. Call providers and ask about their services. Talk to other parents about their BHRS services. Become familiar with different types of therapy through the Internet, bookstores, or local library. Always remember that the type of services your child receives is your decision. This is why it is vital that you do your homework!

BHRS Services are funded by the Department of Public Welfare, through the Medical Assistance card, and managed by a Behavior Health Managed Care Organization (BHMCO). The BHMCO managing the services depends on the county. In Allegheny County, Community Care Behavioral Health Organization (CCBHO) is the managing entity and can be contacted at 412-454-2120. Value Behavioral Health is the managing entity that serves Beaver, Lawrence, Westmoreland, Indiana, Washington, Greene, Butler, Armstrong, and Fayette counties. Value can be reached at 877-615-5803.

(from ABOARD)

Section 6: What are Family Based Mental Health Services?

These comprehensive services are designed to assist families in caring for their child or adolescent at home. Services may include treatment for the child and other family members, case management, and family support services. Services are available twenty-four hours a day, seven days a week and are provided by a team of mental health professionals in the family’s home. Below is a comparison list of Family Based Mental Health Services (FBMHS) versus Behavioral Health Rehabilitative Services (BHRS). Family Based Mental Health Services are available to those on Medical Assistance and/or private insurance.

Family-Based (FBMHS) vs Wraparound (BHRS)

	Family-Based Mental Health (FBMHS)	Behavioral Health Rehabilitative (BHRS)
Therapy Component	Co-therapy team	One therapist
Other Services	FBMHS usually inclusive includes mobile therapy (MT) & Behavioral Specialist Consultant (BSC) functions; use of Therapeutic Staff Support (TSS) on occasion; team an ongoing unit; no separate case management	Possible Behavioral Specialist Consultant (BSC); possible Therapeutic Staff Support (TSS) team usually ad hoc; separate case management
Indications	Out-of-home diversions; step-down from placement	Out-of-home diversion; step-down from placement; other severely emotionally disturbed (SED) children
Guiding Philosophy	Children/Adolescent Service Support Program (CASSP) Principles	Children/Adolescent Service Support Program (CASSP) Principles
Primary Focus	The family unit, including child, siblings, and parents	The child; and parents in relation to child
Primary Technique	Systems therapy—Structural Family Therapy	Varies with therapist
Site of Services	Home and community; specific site(s) based on need	Home, community, school; specific site(s) based on need
Enrollment	Voluntary only; Medical Assistance or non-Medical Assistance	Voluntary only; Medical Assistance only
Coverage	“24/7,” by FBMHS program	Case management and crisis intervention covers after hours
Funding	Back-up/admin time billable	Limited billing of admin time
Supervision	FBMHS director, of entire team.	BHRS provider
Minimum Training	Cohesive 3-year curriculum	Requirements of regulations. No specific curriculum.
Special Uses	More than one child in need; parents identify own problems; parents request FBMHS; multi-system involvement; failure of BHRS.	Child at risk; moderate need; Child needs; Therapeutic Staff Support (TSS) Specific Axis I Diagnosis
Potential Pitfall	Under focusing on child and his/her specific symptoms; aftercare transition	Over focusing on the child’s behaviors; limited therapy with family; service over-utilization

(Taking Charge of Your Child’s Mental Health—A Parent’s Guide, Allegheny Co. Department of Human Services)

Section 7: If Medication is Suggested, What Do I Need to Know?

Sometimes, after children have been in therapy for a while and are not showing significant improvement, it is suggested that perhaps medication should be considered. Caregivers often balk at this suggestion, worried about side effects or possible addiction to the medication. These concerns are understandable and need to be addressed.

The Food and Drug Administration (FDA) and pharmaceutical companies are the organizations that approve medication for children. Psychiatrists can prescribe these medications or prescribe medications not approved for children (off-label). “Off label” indicates that the pharmaceutical company that developed the medication has not shown how well it works for treating children under the age of 18. In either case, it is essential that, when a child or adolescent is taking medication, there must be ongoing evaluation and monitoring by a treatment professional.

The following questions should be asked when you are considering medication for a child/adolescent:

- Will medical tests have to be done before my son/daughter begins the medication? If so, why?
- Will my child become addicted to the medication?
- How long will my child be on this medication—months, years, etc.?
- What are the side effects to this medication? What are the long-term side effects if my child has to take this medication for a long period of time?
- How does this medication work?
- Will my child’s personality change because of this medication?
- What will this medication cost? Is there a generic form of this medication?
- How soon will we know if the medication is working?
- How do you know when to stop the medication or change the medication if it does not seem to be working?
- Has this medication worked for other children with similar problems?

If possible, include your son or daughter in this discussion. Adolescents may be embarrassed about taking medication; information about how the medication works may increase the likelihood that the medication will be taken as indicated. Do not be discouraged if the first medication does not produce positive results. Sometimes a “trial and error” process takes place until the right medication makes a difference. Medication affects individuals in different ways; it often takes time and patience to find the medication(s) that will be most effective. Medication does not “cure” mental illness. Taking medication will often lessen the symptoms and allow the child/adolescent to have a better quality of life. Also, research tells us that therapy combined with medication often produce the most positive results.

A Guide for Caretakers of children/adolescents diagnosed with clinical depression - www.ParentsMedGuide.org

As a parent of a child or teenager diagnosed with clinical depression you might be aware of the recent government decision regarding antidepressants. The U.S. Food and Drug Administration (FDA) has mandated that a cautionary label, a “black box warning,” be placed on all antidepressant medication used in treating depression and other disorders such as anxiety and obsessive compulsive disorder in children and adolescents.

A black box warning is a label indicating prescribing physicians and patients use special care in certain uses of medication for specific conditions or for certain age ranges. The FDA decision regarding antidepressant use in treating children and adolescents does not prohibit the use of these medications, rather it calls for closely monitoring their use with regards to worsening of symptoms, suicidal ideation or unusual changes in behavioral.

In response to this FDA decision, a coalition of medical and family/patient advocacy organizations, including NAMI, have developed a web-based resource center for parents/caregivers of children and adolescents with depression. The ParentsMedGuide.org coalition first convened in November 2004 as a work group of the American Psychiatric Association and the American Academy of Child and Adolescent Psychiatry.

The website includes fact sheets on the use of medications for treating depression in children and adolescents. It also includes practical advice for parents on treatment plan development and effective advocacy tips. In addition to advice for families, the ParentsMedGuide.org site contains a physician’s medication guide, written for practicing physicians seeking the most up-to-date information on pediatric depression, treatment alternatives, and research findings. The general public can access both the information for parents and for physicians.

Section 8: Family and Friends Think I am at Fault for My Child's Behavior—What Can I Do?

Parents of children with mental illness often feel they are to blame for their child's behavior issues. This is often reinforced by family and friends when they are asked to "control his/her behavior" when the child is acting out or not "fitting in" with other children at school or in the neighborhood.

Often parents are made to feel that they are to blame for their child's illness. When a child has diabetes or asthma, parents are not blamed for these illnesses because it is known that these health disorders are caused by a physical problem in the body. Family and friends are often sympathetic and supportive when a child has a physical problem. What must be understood is that mental disorders are a group of individual illnesses of the brain (an organ of the body) that effect behavior, mood, and even the thinking processes.

Mental illnesses are caused by a number of factors. Biological influences can include genetic factors, disturbances that occurred in utero that may have changed brain chemistry, chemical imbalances, brain trauma or severe and prolonged life stress. Mental illnesses are not the result of "family dysfunction" or just a "phase" the person is going through. When a child is diagnosed with a mental illness, parents often examine all facets of their relationship with the child, searching for something they did or did not do that caused this problem. Mental illnesses are not the result of poor parenting or lack of attention towards children. These disorders are treatable and do not need to interfere with development as a child grows and matures.

When we have children, we expect to have a healthy child, physically and emotionally. When a child has a mental illness, parents often feel the loss of the child they expected to have. It takes time to accept that your child may be different from other children and may need special services to deal with the illness. Feelings of loss are normal; it does not mean that you do not love your child. It only means that you are going through the process of accepting your child as he/she is at the present time.

As you work through this process, it is vital that you take action to get your child the services he/she needs. When a child is experiencing symptoms of mental illness, this can delay the development of social skills and also interfere with the learning process. These problems combine to create an inability to relate well with family members, peers, and school personnel. Sometimes, if motor skills are affected, the child will be ostracized from sports and other recreational activities.

If a youngster's mental illness goes untreated and he/she grows into adolescence, the door is open for abuse of drugs and/or alcohol as a means to "self medicate." Other problems begin to surface; decreased self-esteem, year after year of school failure, and rejection from peers that can lead to isolation or anger issues. As things go from bad to worse, there is a risk for developing long-term symptoms that can affect him/her throughout a lifetime.

When a child is getting appropriate treatment (which may include medication), being closely monitored, and receiving appropriate and effective mental health services, the focus will not just be on crisis management but on recovery/resiliency.

How do you deal with people who do not understand your situation? If possible, educate family members and friends about your child's illness. Share resources that you have found to be helpful. Contact NAMI Southwestern Pennsylvania at 1-888-264-7972 to locate a support group in your area. Interested in starting a support group? NAMI can provide technical assistance. Caregivers can also participate in a chat room that many Internet sites now sponsor for parents of children with special needs. You will learn that other parents are going through similar experiences. Resources are often shared at these meetings and website chat rooms. Surround yourself with positive individuals who understand your problems and do not criticize your efforts.

The resource list at the back of this booklet lists organizations that offer support to families with children/teens with mental illness. Contact them and ascertain if they have a support group and if so, when and where do they meet. Also, ask for specific information that you need to understand your child's illness, the mental health system, or the school system.

Section 9: IDEIA – What is a “Free and Appropriate Public Education”?

On November 19, 1975, Congress enacted Public Law 94-192, known as “The Education for All Handicapped Children Act of 1975” which guaranteed the right of all handicapped children to be entitled to a free and appropriate education. Congress amended this Act several times over the years. On June 4, 1997, this act was amended again and renamed “Individuals with Disabilities Education Act of 1997” (IDEA). The amended statute, followed by federal regulation guided the states to write their own statute and regulations. These state statutes and regulations cannot diminish or reduce the rights of special education students and their families that are provided in the federal statute but may provide children and caretakers with more rights and protections. If there is a conflict, the federal law is always followed.

On December 3, 2004 Congress reauthorized the IDEA, now known as the Individual Disabilities Education Improvement Act (IDEIA). Federal Regulations are being written at this time. The states will follow with regulations as well. There are changes in effect at this time (since July 1, 2005) concerning definitions, services prior to identification, evaluating/identifying students, Individual Education Program (IEP)/Free Appropriate Education (FAPE), highly qualified teachers, transition, enactment dates, discipline, and procedural safeguards.

Listed here is current information from the IDEIA (federal statute). Federal Regulations are being written at this time that may broaden the scope of the federal statute. The following information is in effect *as of August 31, 2005. For more up to date information, log onto www.elc-pa.org.*

Is my child eligible for special education?

As a parent or caregiver, you know your child better than anyone. You are aware of weaknesses and strengths, triggers that upset your child or cause him/her to feel comfortable, and how to create the environment in which your child can thrive and grow. It is essential that school professionals use your valuable information in the evaluation process and the development of a special education program. Under the reauthorized IDEIA regulations, a parent must be a part of the IEP team for planning and implementation. Parents and caregivers should always put their concerns and input in written form and dated when communicating with the school or with any service provider.

Your child may be eligible for special education if your child:

- Has a disability. In IDEIA, the evaluation team no longer has to determine if a child has a particular disability but only if a child is “a child with a disability.” This allows school districts to offer services to young children (age 3-9) regardless of whether the child has been diagnosed with a specific disability.
- Needs special education as determined by the evaluation team of which you are a member.

If your child meets both qualifications, he/she meets the criteria that allow the evaluation team to recommend your child for a special education program. All children eligible for special education have the right to a free appropriate public education (FAPE).

How will I know if my child has a disability?

Some indications that your child has a disability are:

- Behaviors that disrupt your child's ability to learn (cannot concentrate for any length of time, often aggressive, often moody, no longer interested in activities that were once enjoyed).
- Difficulty in getting along with others or no desire to socialize with others.
- Does not participate in age appropriate activities.
- Insists on maintaining routine; resistance to change.
- Communication problems; processes information slowly, non-verbal, difficulty in communicating needs or ideas.
- Hearing or sight problems.
- Health issues that effect the ability to learn.
- Ongoing, severe behavior problems at home but able to function at school where routine is followed and peer pressure promotes suitable behavior.

If my child is showing signs of a problem, what can I do?

Your first step is to request an evaluation from your school district. This request needs to be in **written form** and sent to the principal of the school. In your request letter you will:

- Request an evaluation for your child.
- Give permission for your child to be evaluated.
- Make sure the date you sent the letter is clearly marked on your letter.

The entire evaluation process must be completed within *60 calendar days* of the receipt of the letter by the school district. You can request an evaluation at any time. You can get an independent evaluation (outside of the school district), but the law states that school districts can "consider" the outside evaluation. A school psychologist will conduct the evaluation, using testing data, information from teachers, information from caretakers, observations in the classroom, and, possibly review of any previous evaluations you have provided. All testing by the school district is free of charge. Your child will be reevaluated every three years unless you request an evaluation within that time period. Children with mental retardation are evaluated every two years.

What is done with the results of the testing?

You will be notified when the tests are complete and the psychologist is prepared to share the findings. This evaluation will include data about your child's skills, social behavior, learning

problems, learning strengths and weaknesses, and education needs. The results will be reviewed at an evaluation team meeting. Be sure that all testing is explained; especially test scores and what they may indicate about your child's learning problems. Feel free to ask questions for clarification purposes. If you disagree with something in the evaluation report, be sure to share this with the team. The evaluation report will indicate if your child needs special education. This report may recommend the type of programs and services your child needs. The Evaluation Report may state that your child is ineligible and does not need a special education program.

What does the IDEIA say about Special Education?

When your child is deemed disabled and it is decided that he/she is eligible for special education services, he/she has a right to special education and related services that are provided:

- At public expense.
- Under public supervision and direction; school districts must provide "highly qualified teachers" to provide education.

In accordance with the Individual Education Program (IEP), which has been developed by the IEP team. All students deemed eligible for special education are entitled to a free and appropriate public education (FAPE).

Section 10: What is an Individualized Education Program (IEP)?

The IEP is a written contract stating the plan that will be implemented to educate the child. This plan is written at a meeting, which includes parents, and will include a description of your child's present levels of performance, description of all programs, yearly goals for each program (except for those taking alternate assessments), and transition plans for adolescents (age 16) for each program. It is helpful to include a description for the present levels of performance on each program page that will list goals in that area. Information gleaned from the evaluation report will be incorporated into the IEP.

IEP meetings must be scheduled to fit your schedule and those who will be attending from the school district, mental health services, and anyone you deem necessary for this meeting. You will get written notice of this meeting. If you cannot attend, you will need to notify the school district immediately and the time will be changed. It is imperative that you attend this meeting. If you choose not to attend the IEP meeting, the meeting will be held without you. **The IEP must be developed within 30 calendar days after the evaluation team issues the evaluation report.** Your child's IEP will be reviewed every year at an IEP meeting or more often if you or any other member of the team requests another meeting be held. **Put all requests in writing.**

What goes into the IEP?

One page in the IEP will list your child's present level of performance. Be sure the content of this page is not all subjective. Current tests results should be listed showing improvement or lack of improvement in all areas. Remember you can add your own information in this section. Annual goals will be determined for each section of the IEP. Short-term objectives have been removed from the IEP except for students who are taking alternative assessments.

A word about assessments: The No Child Left Behind Act of 2001 was designed to improve student achievement and close achievement gaps. The state and all local schools must use the academic content and achievement standards to create "continuous and substantial standards to create continuous and substantial academic improvements for all students." This improvement must be sufficient to "ensure that all students will meet or exceed the State's proficient level of academic achievement or the State assessments within the State's timeline (NCLB20 U.S.C. Section 63311[b][2]). In Pennsylvania, the Pennsylvania System of Assessment (PSSA) is the state assessment given to all students in Pennsylvania. Every Pennsylvania student in 3rd, 5th, 8th, and 11th grade is assessed in reading and math. Every Pennsylvania student in 5th, 8th, and 11th grade is assessed in writing. The severity of the disability will indicate if your child will take an alternative PSSA test. If your child takes the alternative PSSA, the IEP must include short-term objectives for each category.

The IEP should include:

- Services and programs provided for your child. The education tools used must be researched based with measurable outcomes.
- Where, what kind of, and how often special education and related services will be provided.

- The date services and programs begin and end.
- Methods of evaluation that are measurable, not subjective, and how progress will be reported.
- Consideration of least restrictive environment. Children with disabilities are to be educated with their peers as much as possible. How much, if any, the student will not participate with the regular education curriculum—when and where your child will be in other settings, when your child will not be studying skills or knowledge that are directly linked to the skills and knowledge studied by children in general education.
- Accommodations in the general education class to ensure successful outcomes for your child.
- Accommodations, if needed, for your child to take the PSSA. Your child’s participation in the alternate PSSA will be documented in the IEP.
- At age 16, the transition page must indicate a results oriented plan; must address the academic, developmental, and functional needs of the student; must contain measurable post-secondary goals based on age appropriate assessments; goals must relate to training, education, employment, independent living skills, and needed transition services. The school district is no longer required to make linkages for students, but parents can easily fulfill this role.
- Extended School Year Option—If interruptions in the school schedule result in your child losing skills learned in the school year or if your child has emerging skills at the end of the school year and will lose these skills during a break, your child is eligible for Extended School Year. The plans for Extended School Year should be made by mid-March. It is wise to document your child’s timeline for regaining skills when a break occurs (holidays or summer breaks) so that you can state evidence if there is a question as to whether your child is eligible.

What is the Notice of Recommended Educational Placement (NOREP)?

So far in this section you have learned:

- You must request that the school evaluate your child in writing. In this letter, you must request the evaluation and give permission for the evaluation to take place.
- School Evaluation: You will be notified when the evaluation is completed. The evaluation will include data about your child’s skills, social behavior, learning problems, learning strengths, weaknesses, and education recommendations.
- The evaluation team (includes parents) decides if your child meets eligibility requirements for Special Education.
- If your child is eligible, an IEP will be developed by the IEP Team.

When the IEP is completed, this document should indicate to the EIP team where your child’s education will take place. First and foremost, the least restrictive environment (LRE), which is the regular education classroom, must be considered as the first choice. The team will decide how much time your child will spend in regular education versus special education classes. This

will be indicated on the Notice of Recommended Educational Placement (NOREP). You must approve the IEP and chosen placement in writing before the plan can be implemented.

A word about inclusion: Every child with an IEP is entitled to receive a Free and Appropriate Public Education (FAPE) in the least restrictive environment (LRE). The first choice would be the regular education class. In most cases, a child's IEP can be developed in such a way that he/she could stay in the classroom with the same aged peers. These children often need modifications, an adapted curriculum, or an aide to assist them. Recent case law in Pennsylvania has strongly supported inclusive education for all disabled children. Some children spend part of their day in regular education and part of their day in special classes (Learning Support, Emotional Support, Life Skills, Sensory Support, Speech and Language Support, Autistic Support, Physical Support, and Multiple Disabilities support class). After the IEP, the team will decide the best placement for the child. A stipulation in the IEP will indicate the amount of time spent in regular education and the amount of time spent in special education.

What about discipline problems?

Children cannot be disciplined using restraints, locked rooms, suspensions, or removal from classes as a constant solution to bad behavior. School staff cannot withhold meals, water, or fresh air. At times, teachers have been known to withhold recess as a consequence for behavior problems. This is not a good practice since all children need this time to unwind and relax after working for several hours, especially those with mental illness.

- If your child is removed from school because of a discipline problem, the school district must continue to provide a Free Appropriate Public Education (FAPE). This is considered a change in placement; the IEP is still to be followed.
- If your child has been expelled for more than 10 school days in a row or 15 accumulated school days in any one school year, the IEP team must meet and a Notice of Recommended Educational Placement (NOREP) must be signed. (The expulsion of a child with mental retardation for any amount of time is considered a change in placement.)
- If you do not agree with the change in placement, your child stays in the placement as you request a due process hearing.

What is a Manifestation Determination Meeting?

If your child has been expelled for more than 10 school days in a row or 15 accumulated school days, the school district is required to have a Manifestation Determination Meeting. This meeting:

- Must be held within 10 school days of any decision to change placement. Those participating in this meeting include caregivers and relevant members of the IEP team.
- This team will review all relevant information to determine if the conduct of your child was caused by or had a direct and substantial relationship to the disability, or the behavior was a direct result of the school's failure to implement the IEP.

- You as a caregiver have the responsibility to prove that the behavior was a result of the mental illness.
- If those attending this meeting decide that your child's disability has caused the behavior in question, the district must conduct a Functional Behavioral Assessment (FBA).
- The FBA is a thorough examination of the behavior which involves information gathering from all who have observed the behavior. This information will be used to understand how this behavior benefits the student. There will be a thorough description of the behavior, the antecedents and consequences that are present at the time of the behavior, and how this behavior benefits your child. Unfortunately, there is no timeline for the FBA in the IDEIA.
- If the individuals attending this meeting decide the behavior was caused by a mental illness, your child would be returned to his/her previous placement unless a new placement is agreed upon by all members or the child was removed from placement for "special circumstances." "Special circumstances" include "serious body injury upon another person," finding a weapon, and/or finding illegal drugs/controlled substance which allows the school to immediately remove your child to an alternative placement for up to 45 school days. Your child is still entitled to FAPE, the IEP must be followed, and services must be put in place to deal with the behavior so this does not happen again.

Section 11: Due Process Rights

You or the school may request a re-evaluation. This request may be to request a mediation session or due process hearing to resolve differences between you and the district.

What is Mediation?

The state maintains a list of qualified mediators to conduct mediation sessions between caregivers and school districts. The site for the session is to be convenient for both parties. All discussion is confidential and may not be used as evidence at a due process hearing. Attorneys cannot be present for mediation. You and the school district can invite only those they feel can contribute to the understanding of the situation; advocates are permitted to attend. The mediator will hear both sides separately and then reconvene all concerned to try to resolve the issue. If the two parties agree on a resolution, the mediator will design a legally binding agreement that explains the resolution and states the information presented at the session cannot be used as evidence at a due process hearing. You and the representative of the school district must sign the agreement. The agreement is enforceable in any state and federal court.

What is a Due Process Hearing?

When issues between you and a school district cannot be resolved, you can request a due process hearing. As of August 2005, you will need to request in writing a due process hearing to take place as soon as possible. The hearing must be held within 30 calendar days after the request before an impartial Hearing Officer. This request must be made within two years of the date the parent or school district knew about the problem. The school district will contact you concerning the date and time of the hearing. Both sides may have attorneys present. It is advisable that you hire an attorney who specializes in education law. The IDEIA has made some changes in due process procedures; an attorney specializing in education law should be aware of these changes. Contact the Education Law Center at 412-391-5225 for a list of education law attorneys in your area.

Section 12: What is a 504 Service Agreement?

Section 504 of the Rehabilitation Act and the Americans with Disabilities Act is civil rights law. Section 504 protects individuals with disabilities from discrimination that arises because of their disability. A 504 Service Agreement is considered when a child has disability that can limit at least one major life activities, which can include walking, seeing, hearing, speaking, breathing, learning, reading, writing, performing math calculations, taking care of oneself or performing simple manual tasks. If your child does not meet the criteria for special education, he/she may be eligible for a 504 Service Agreement.

A 504 Service Agreement often contains a list of accommodations and modifications that can assist the child with disabilities in the classroom. Without this assistance, the child would not succeed. The basis for establishing these accommodations and modifications is to prevent discrimination that would prevent a child/teen from accessing the learning process.

A 504 Service Agreement does not provide:

- Individual Education Program (IEP).
- Procedural Safeguards of the Special Education System.
- Discipline Protections.
- Prior Written Notice of Change of Placement.

A 504 Service Agreement does provide:

- Accommodations and modifications to assist learning. These can include providing a structured environment, repeating instructions, and simplifying instructions, modifying tests, visual instructions, modifying homework, using tape recorders, using modified textbooks and/or workbooks, classroom aide, modification of nonacademic time, using notes of other students, and others.
- Improved building accessibility.

Section 13: Advocacy Tips for Caregivers of Children/Adolescents

Many of us learn advocacy from our own life experiences. We often “go to bat” for another person we feel needs our support. Caregivers of children with special needs have realized that they have the power to advocate for services within the education and mental health systems and that this advocacy can make a difference in their child’s life. Listed below are effective advocacy tools a caretaker can use that will assist you to become a powerful advocate for your son or daughter.

- Become knowledgeable about your child’s illness and your rights as a caregiver. Join organizations (such as NAMI Southwestern Pennsylvania) so that you can access books, journals, and films to learn about your child’s illness. Peruse websites listed in this handbook to find information on the illness, medications, treatment options, education law, and the mental health system.
- Create organized files of your child’s records (medical records, records of communication between you and other parties, samples of school work).
- Keep files on IEPs (Individual Education Program), Family Service Plans, and Evaluations.
- Make sure all correspondence must be in written form (schools, insurance companies, community organizations) and keep dated copies in your file.
- Keep a telephone log of when and to whom you speak.
- Be sure to invite your child’s case manager, therapist, behavior consultant, therapeutic staff support, psychologist, psychiatrist, or advocate to assist you through this process.
- Before attending a meeting, make a list of all your concerns, goals, and ideas that you can contribute to the conversation (you are the best authority on your child).
- Use appropriate communication; begin sentences with “I” instead of “you” to reduce blame and defensiveness.
- Ask for meeting breaks if you feel you are losing your patience. Remember losing your temper will not resolve any problems.
- Listen to what others have to say even if you disagree with their ideas. You can respect another’s opinion even though you may not agree with what is being said.
- Remember you are speaking for your child; do not get caught up in “winning.”
- Surround yourself with support (friend, relative, advocate, etc.)

It is natural to be nervous when attending an important meeting that may impact your child’s mental health or education services. Even if you are very knowledgeable, you will not be effective if you cannot present your ideas clearly and with confidence. Consider the following tips on how to be assertive and communicate effectively during meetings concerning your child.

Section 14: Resources

Disability Information & Family Organizations

- **Advisory Board on Autism and Related Disorders** – www.aboard.org
Offers information on Autism Spectrum Disorders, up-to-date training schedule, and support group information.
- **American Academy of Child and Adolescent Psychiatry** – www.aacap.org
Offers fact sheets, current research on mental illnesses that effect children and adolescents.
- **Child and Adolescent Bipolar Foundation** – www.bpkids.org
Parent-led, not-for-profit web-based membership organization that features an online learning center, message board, chat rooms, support groups, database of treatment providers.
- **Children & Adolescents with Attention Deficit/Hyperactivity Disorder** – www.chadd.org
Provides evidence-based information about ADHD to parents, educators, and professionals.
- **Council for Exceptional Children** – www.cec.sped.org
This site features information on IDEA, has an information center on disabilities and gifted education, and resources for professional development.
- **Federation for Families for Children’s Mental Health** – www.ffcmh.org
This is a national family-run organization that assists children/adolescents with mental health needs. Offers training programs for family members.
- **Learning Disabilities Association** – www.ldanatl.org
Site offers information for parents, teachers, professionals, and adults covering a wide variety of learning disabilities. Lists resources and state chapter information and on-line IDEA training course for parents.
- **National Eating Disorders Association** – www.nationaleatingdisorder.org
This site features an effective checklist entitled “Get Real,” current research information and advocacy tips.
- **Parents Involved Network of Pennsylvania** – www.pinofpa.org
This site is a statewide support, advocacy, information, referral, and technical assistance resource center for families who have children and/or adolescents with emotional or behavioral disorders.
- **ParentsMedGuide** – www.parentsmedguide.org
This site includes fact sheets on the use of medications for treating depression in children and adolescents, advice on treatment plans, and advocacy tips. Also features a guide, “PhysiciansMedGuide,” for general practitioners on the use of medications for depression.

- **Schwab Foundation for Learning: “A Parent’s Guide to Helping Kids with Learning Difficulties”** – www.schwablearning.org
Site offers parents a guide to helping children/adolescents with learning disabilities. Offers on-line newsletter information on identifying learning difficulties, managing issues that arise from having a child with learning difficulties, support information, message boards, and resources.
- **Special Kids Network** – www.health.state.pa.us/skn
Sponsored by the Pennsylvania Department of Health, this site maintains a database containing thousands of referral resources including information about local, state, and national agencies.

Advocacy

- **Education Law Center of Pennsylvania** – www.elc-pa.org
Located in Philadelphia, Pittsburgh, and Harrisburg, the ELC is a non-profit legal advocacy organization. Site has current information concerning national and state regulations and phone numbers to call for questions about education law.
- **Parent Education Network** – www.parentednet.org
Site with publications concerning advocacy tips, navigating the education system, transition, parent guide to special education, and more.
- **Pennsylvania Department of Education** – www.pde.psu.edu
This site provides information about state initiatives, special education issues, and state approved forms for services provided by school districts. Site visitors can communicate directly with the department. Also includes links to all school districts and Intermediate Units. This site also includes the **Special Education Consult Line**. This is a direct line to a special education specialist who can explain laws relating to special education, describe the options available, inform parents of procedural safeguards, identify other agencies and support services, and describe available remedies and how parents can proceed. Hours: 8:00 AM-4:00 PM, Monday through Friday; no pager numbers - **1-800-879-2301**.
- **The Pennsylvania Health Law Project** – www.phlp.org
Provides free legal services and advocacy to Pennsylvanians having trouble accessing publicly funded health care coverage. For assistance contact the toll-free help-line at 1-800-274-3258.
- **Pennsylvania Training and Technical Assistance Network** – www.pattan.k12.pa.us
The PA Training and Technical Assistance Network (PATTAN) is an initiative of the Pennsylvania Department of Education, Bureau of Special Education. This site offers professional development that builds the capacity of local education agencies to meet student’s needs. Sometimes, trainings include family members.
 - **Office of Dispute Resolution** – www.pattan.k12.pa.us/ODR/
Coordinates and manages Pennsylvania’s special education mediation and due process system - 1-800-222-3353.

- **Wrightslaw** – www.Wrightslaw.com
Parents, advocates, educators, and attorneys can find accurate, up-to-date information about special education law and advocacy tips.