Tips For Effective Advocacy in Getting or Keeping Behavioral Health Services for Your Child



Get Organized and Keep a Record!

At times it may seem you are the only person who knows what is going on with your child's care, and even you are having trouble keeping it all straight! You get different messages from people who should be talking to each other. Your child's MCO says they didn't get faxes or letters that you know that you sent. You have talked to so many people that you can't remember what each one has said. And there are tons of papers to sort through. Here are a few tips that may help:

- 1) **Keep a notebook** where you record information about your efforts to get the services you are seeking. Your notes should include:
 - ✓ names of every person you speak to about your effort to get services
 - ✓ their telephone numbers
 - ✓ when you called (date and time)
 - ✓ what was discussed
 - ✓ what each of you agreed to do as a result of the conversation
 - ✓ next steps for you
- 2) **Keep a file or a three ring binder** where you put any written documents that you get or send about your child's need for services and your effort to get services. If you can organize it by the kind of doc ument and the date on the document this may help you find things when you need them. This file should include:
 - ✓ Correspondence: Letters, faxes, and print-outs of e-mails that are sent to you by any providers, MCO representatives, State or County Officials and any letters, faxes, print-outs of e-mails that you send
 - ✓ Evaluations: Any written evaluations of your child and supplements to evaluations

- ✓ Treatment plans
- ✓ TSS progress notes
- 3) Get and keep the fax confirmation page, if you send a fax. The fax confirmation page says that your fax went through to the person you are sending it to. If you haven't saved your fax confirmation pages, you may still be able to get a record of the faxes you have sent by having your fax machine print a log of the faxes it has sent.
- 4) **Do not send your original documents to anyone!** Keep the originals for your records, send <u>copies</u> to the MCO, providers, the Hearing Officer etc.
- 5) **Make all of your requests in writing.** If you make a request over the telephone or in person, follow up that request with a written request.
- 6) Be Prepared. Carefully read the evaluations, treatment plans and other documents about your child so that you know what is in them.
- 7) Know the beginning and ending dates of your child's authorized services. If you aren't sure call the MCO representative involved with your child's case to find out.
- 8) Know when your child is due for a re-evaluation (when the next psychological or psychiatric evaluation should be done). Again, if you aren't sure call the MCO representative involved with your child's case to find out.

Communicate Effectively

1) Communicate regularly with your child's providers.

Try to communicate regularly with your child's behavioral health providers to make sure that you and they all agree on your child's treatment needs and that everyone is working toward the same goals.

2) **Create positive relationships with those who can assist you.**Often your child's treatment team, staff at her school or daycare, individuals

at the County Mental Health office and others can be extremely helpful in supporting your efforts to get the right care for your child.

- 3) **Be as polite, respectful and flexible as possible but be persistent.** If you are not getting anywhere with a particular individual, ask to speak to their supervisor.
- 4) Don't be afraid to ask for something to be repeated, to admit you don't understand, or to ask that it be put in writing.

Other Resources

PIN of PA – The Parents Involved Network, a project of the Mental Health Association of Pennsylvania helps families by answering questions and providing support. PIN can be reached at 1-800-688-4226

Your County CASSP Coordinator – CASSP stands for "Child and Adolescent Service System Program." If you don't know who the CASSP coordinator is in your area, call your county's Mental Health Office – they will direct you to the right person. The CASSP coordinator is supposed to ensure that children and adolescents who need mental health services get appropriate services that are:

- child-centered and family focused
- provided in the community whenever possible, and
- provided in the least restrictive or intrusive setting appropriate for your child.

The CASSP Coordinator should also work to ensure that:

- services are planned in collaboration with all other agencies and systems involved in your child's life, and
- services recognize and respect the behavior, ideas, attitudes, values, beliefs, customs, language, rituals, ceremonies and practices characteristics of the child's and family's ethnic group.

If you are not able to get the help you need from your local CASSP Coordinator, you can contact the **Regional Office for the Office of Mental Health and Substance Abuse Services (OMHSAS) and talk to their Children's Specialist**.

Southwest Field Office 412-565-5226 for the counties of Erie, Warren, McKean, Potter, Crawford, Venango, Forest, Elk, Cameron, Mercer, Clarion, Jefferson, Clearfield, Lawrence, Butler, Armstrong, Indiana, Beaver, Allegheny, Westmoreland, Greene, Fayette, Washington

Central Field Office 717-705-8395 for the counties of Clinton, Lycoming, Columbia, Centre, Union, Montour, Snyder, Northumberland, Mifflin, Juniata, Cambria, Blair, Huntingdon, Perry, Dauphin, Cumberland, Lebanon, Somerset, Bedford, Fulton, Franklin, Adams, York, Lancaster

Northeast Field Office 570-963-4335 for the counties of Tioga, Bradford, Susquehanna, Wayne, Sullivan, Wyoming, Lackawanna, Pike, Luzerne, Monroe, Carbon, Schuylkill, Berks, Lehigh, Northampton

Southeast Field Office 610-313-5844 for the counties of Philadelphia, Chester, Montgomery, Bucks, Delaware

The Pennsylvania Health Law Project (PHLP) – www.phlp.org or the toll-free Helpline 1-800-274-3258

- PHLP is a statewide center of legal expertise and advocacy devoted to helping low income, elderly and people with disabilities gain access to quality health care.
- PHLP provides free services to families needing help getting mental health and drug & alcohol services for their children or themselves.

Your Child's School

 Meeting <u>educational</u> goals is not the responsibility of Medical Assistance (or the BH-MCO) but rather is the responsibility of your child's public or private school. Educational goals include: progress with academic subjects like spelling, reading, or math.

- There may be services or programs available to your child through the school system.
- Contact your child's teacher, guidance counselor, principal or the Student Assistance Program to find out how to get help through the school.
- If your child is not yet of school age, contact the Intermediate Unit in your area to find out what early intervention services your child is eligible for.

Disabilities Rights Pennsylvania (DRP) – www.dlp-pa.org 800-692-7443

- DRP provides free legal assistance to people with disabilities, their families, and their organizations.
- DRP's main purpose is to advocate for the civil rights of persons with mental and physical disabilities, especially their right to live as integral parts of their communities.