



# What's Happening at MLRA... March 2011



## Main Line Rehabilitation Associates CODE OF ETHICS

Main Line Rehabilitation Associates' Code of Ethics directs staff to protect the welfare of consumers, respect the integrity of the individual, and advocate for the client's rights. In doing so, the individuality, privacy, and personal goals of each consumer are respected and protected.

## SOCIAL SECURITY BENEFITS

The federal government pays disability benefits under two programs:

- The Social Security Disability Insurance (SSDI) program pays benefits to you and certain family members if you worked long enough and paid Social Security taxes.

Your adult child also may qualify for benefits on your earnings record if he or she has a disability that started before age 22.

- The Supplemental Security Income (SSI) program pays benefits to disabled adults and children who have limited income and resources.

SSI benefits are also payable to people 65 and older without disability who meet the financial limits.

For most people, the medical requirements for disability payments are the same under both programs and disability is determined by the same process.

Call **1-800-772-1213** (TTY **1-800-325-0778**) or contact your local Social Security Office for information.

*Main Line Rehabilitation Associates is a  
CARF Accredited Home & Community Based Brain Injury Program*



## **Statement of Protection of Individual Rights and Responsibilities**

It is the policy of Main Line Rehabilitation Associates, Inc. that the rights of all individuals will be fully recognized and protected. Individuals served and other appropriate parties are informed of these Rights and Responsibilities prior to admission. These rights are reviewed yearly with individuals served through publication in our Outreach newsletter. The following rights are guaranteed to all individuals applying for or receiving services through Main Line Rehabilitation Associates, Inc.

### **Individual Rights**

- Person centered, clinical services will be provided without regard to race, color, religion, sexual orientation, handicap, language, ancestry, national origin, age or sex.
- Each individual will be provided the opportunity to choose services and staff. Individuals are asked to give informed written consent to accept or refuse treatment.
- Each individual and legal guardian will be fully informed in writing at the time of admission and during services of any changes in those services.
- Individuals will be provided with assistance to access self-help, advocacy and legal services.
- Each individual will be encouraged and assisted to exercise his/her rights as an individual being served by Main Line, and as a citizen, including voting in public elections.
- Main Line does not prescribe or administer any drugs.
- Each individual (or legal guardian) is responsible for choosing where to live and with whom they live. Main Line will make recommendations regarding living arrangements if requested to do so by individual, guardian or funding source, however, the individual or guardian will be responsible for decisions made regarding living arrangements.
- Each individual (or legal guardian) is responsible for managing personal financial affairs. Assistance is available if requested.
- Each individual has the right to engage in the activities of his/her choice; however, if Main Line has concerns about safety, formal recommendations will be made.
- Each individual has the right to decline to participate in research.

- Upon request, each individual will receive information, including evaluations and treatment, in a timely way so as to facilitate the decision making process.
- Each individual may voice complaints or submit recommendations concerning policies and services to Main Line, the Pennsylvania Human Relations Commission and to outside representatives or his/her choice, free from restraint, interference, coercion, discrimination or reprisal.
- Each individual will be free from abuse, financial or other exploitation, retaliation, humiliation and neglect.
- Each person will be treated with consideration, respect and dignity with full recognition of individuality. Privacy will be provided during treatment.
- Each individual will be ensured confidential treatment of all information contained in his/her record, including any stored in a computerized data bank. Written consent will be obtained before information is released from these records to anyone otherwise not authorized by law to receive it.
- All allegations of an infringement of individual rights by Main Line staff will be documented on an incident report form. This will be reviewed by the Clinical Director who will make appropriate recommendations for investigation and resolution.

### **Individual Responsibilities**

- Each individual or legal guardian will assume full responsibility for any actions of the individual and consequences of those actions, if actions are contrary to the individual's defined therapy program.
- Individuals served participate voluntarily and actively in their services. Services are provided with a person centered approach in which the individual's input is the priority.
- Individuals should report any infectious diseases to Main Line staff.
- Individuals should treat Main Line staff in a respectful manner at all times.
- All firearms must be empty (no bullets) and locked (gun lock or locked box) at all times when staff are in the home.
- Individuals should notify the Main Line office of any changes in their medications, their schedule or changes in their eligibility for treatment.
- Individuals must meet eligibility for treatment during the course of the rehabilitation services.

## **FROM THE CLINICAL DIRECTOR.....**

### **Sexuality after BI**

There's no avoiding it, sex is one of the most important topics. Simply put, it is an important part of our lives. It is a source of pleasure and a way to be close to others. It can be a way we connect to those we love most. Sexuality often changes after brain injury, and is often unaddressed in the rehabilitation process.

There are many common sexual problems reported after a brain injury. Changes in libido (some hyperactive and some under active), erectile and orgasmic dysfunction, decreased feelings of self-esteem and personal sex appeal, depression, changes in menstruation and fertility problems are all commonly reported problems.

The presence of depression and age are predictors for increased sexual difficulties for people with brain injuries. Couples often report that role changes, coupled with physical, cognitive, and behavioral changes associated with the brain injury, make connecting sexually more difficult. Often, these changes are a further source of stress in the relationship, especially when not acknowledged.

Consider discussing the topic with a doctor or therapist. Don't avoid the conversation or avoid using proper protection because you are embarrassed. You can ask your staff member to help you to word your request to the doctor if you are unsure of what to say. This shouldn't be a taboo topic if it is discussed maturely.

- Decide what you want to ask your healthcare professional.
- Determine what the important background information may be.
- Ask for information over and over and in a variety of ways (repetition and over-learning are often important tools) if needed.
- Role-play to practice discussions you may want to have with a potential partner.

It is important to be open, honest and direct when addressing this topic, but it will also be important to listen to the feedback you are getting in order to improve your success in meeting your personal needs.

*Bridget Lowery*

Institute on Disabilities at Temple University presents:  
**THE MINI COURSE LECTURE SERIES ON DISABILITIES -**  
Siblings: Moving Beyond the Parent/Child Relationship

The course is a family-oriented discussion about social networks for individuals with intellectual and developmental disabilities. Individuals with intellectual disabilities, family members, professionals, and allies are welcome. Kate and David Fialkowski will share their journey from typical siblings to when one sibling takes on the role of caregiver or overseer of the other sibling. This frank and sensitive discussion will include the transition from parent-lead support to sibling-lead support and navigating the process and outcomes of that role change.

Kathryn Fialkowski and her brother David grew up in inner-city Philadelphia. Kate has spent her life advocating for disability rights and inclusion. She and her family have led grassroots activism in the right to education, community living, and employment for individuals with developmental disabilities.

**When:** Monday, March 28, 2011

Two-Part Session (with lunch on your own)

Registration begins at 9:00 AM

Part I: 10 AM - 11:30 PM

Part II: 1 PM - 2:30 PM

During the afternoon, a select panel will discuss the development and leverage of the social network. Everyone is encouraged to attend including Person-Centered Circles. Questions and open sharing of ideas from the audience will be encouraged.

**Where:** Temple University Main Campus /Student Center

1755 N. 13th Street

Room 200A

Philadelphia, PA 19122

Event is FREE however registration is REQUIRED. Register NOW ONLINE at - [www.disabilities.temple.edu](http://www.disabilities.temple.edu). You MUST register by March 11 if you are requesting accommodations. Materials available in alternate formats upon request.

## ADVICE FOR DEALING WITH DOCTORS

Dealing with doctors can be challenging. It is easy to feel as if you are not getting your point across well, that you don't understand what is being said, and that you leave more frustrated than when you arrived.

### Here are some pointers that may be helpful:

#### **1. Keep a journal of your symptoms and medications.**

We take for granted that we will remember everything that we are experiencing when we are unwell, but the reality of it all is that our memory is sometimes a poor recorder. It is important to have accurate information to share with your doctors.

#### **2. Be prepared for the appointment.**

Make sure you begin preparation for the appointment at least a week in advance to allow for time to formulate your questions and to be sure you addressed all the things that you want your doctor to know.

#### **3. Take a friend, family member, or professional.**

It is true what they say, there is power in numbers! If you are concerned that you are not communicating effectively with your physician or that you need some extra support, don't hesitate to take someone along that you trust.

#### **4. Write down the doctor's responses and clarify what is said.**

Make sure that you have plenty of room to write down the responses to the questions that you have for your physician and do so right away. Also, be sure to state back to your doctor exactly what you heard before you write it down. Sometimes doctors talk to us with complicated medical jargon and we don't always know what they mean.

#### **5. Communicate when you are getting frustrated and why.**

Don't hesitate to tell a person that you are getting overwhelmed, but be sure that you are able to tell them in a respectful way. An example is: *"I'm sorry but you gave me too much information, can we review that again?"*

## **6. Take your time**

It is easy to feel rushed when we visit our doctors. Doctors typically schedule no more than 15 minutes for each patient. Prior to your doctor coming in to meet with you, you will notice that a medical assistant or nurse meets with you first. Take that opportunity to express to that individual some of the questions that you have and that you may need their assistance.

## **7. Review that information often**

Remember that you wrote that stuff down for a reason, so review it as often as you need to so you can be sure that you have a full understanding of diagnosis and treatment.

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## **The Use of Compensatory Strategies**

Compensatory strategies are designed to make daily tasks easier. One of the simplest examples of a compensatory strategy is a calendar. The use of a calendar to write down appointments can assist with remembering appointments, but also can help you manage your time more effectively. Other examples of compensatory strategies include the use of home budgets, memory journals, sleep logs, weekly meal plans, medication boxes, alarm systems, to-do lists, and pictures.

While your facilitator can describe a host of useful strategies, your input will help determine whether or not this strategy will work well for your individual lifestyle. It is important to keep an open mind when it comes to compensatory strategies. It may take time for certain strategies to work or for you to get used to using the strategies on a daily basis. You may find that a strategy that you thought would never work is actually the one that helps you the most. It is also important for you to be aware of what strategies are in place, why you are using them, and the end goal for that strategy. If there is a strategy out there that you are interested in trying or if one of your strategies just isn't working, discuss your concerns with your facilitator.