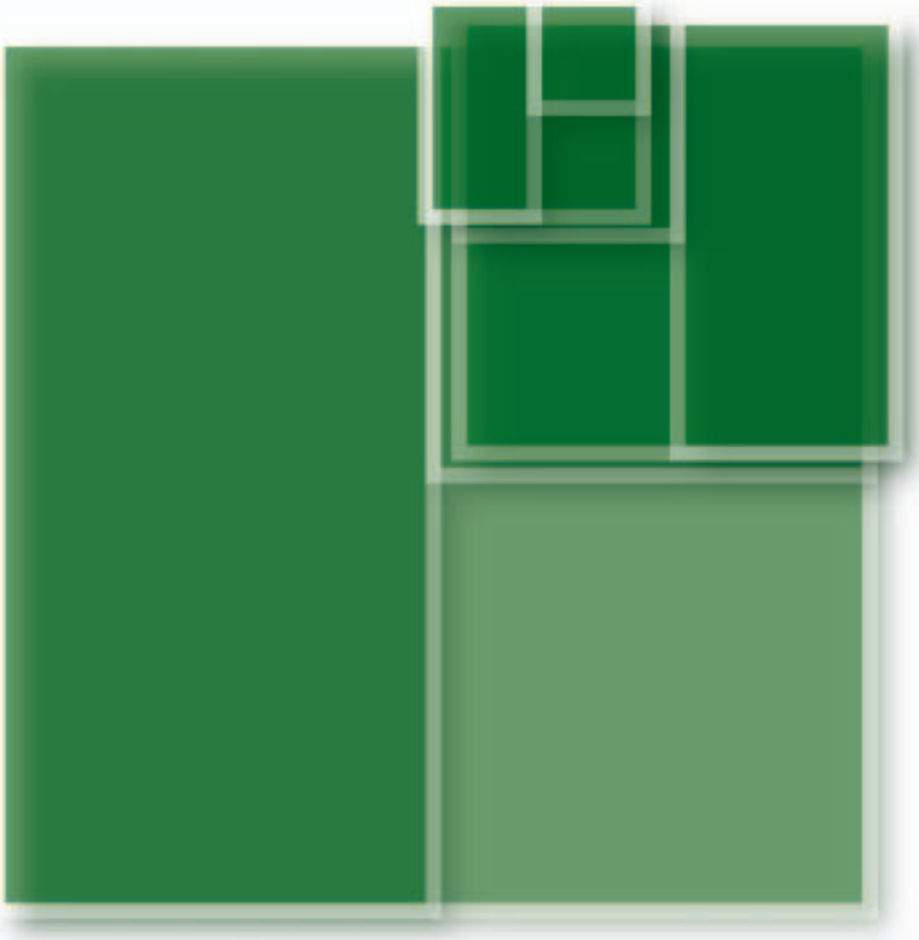
Dealing with Cognitive Dysfunction

Associated with psychiatric disabilities

A handbook for families and friends of individuals with psychiatric disorders



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Associated with psychiatric disabilities

A handbook for families and friends of individuals with psychiatric disorders

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http://www.omh.state.ny.us/omhweb/resources

Forward

EVERY PROJECT HAS A BEGINNING – this Handbook started a number of years ago with the vision of Rami Kaminski, MD, New York State Office of Mental Health, Liaison to Families. Dr. Kaminski understood that it was important for families and other advocates to learn more about cognitive problems associated with mental illness.

With the support of James Stone, the Commissioner of the Office of Mental Health and the dedication and professional skills of Joan Shanebrook, ACSW, Deputy Director in the Family Liaison Bureau at the Office of Mental Health this project moved forward.

There are many individuals to thank for their contributions to this Handbook, but foremost we would like to mention those individuals with psychiatric disorders and their families and friends who have shared their experiences with us in developing this Handbook. Special thanks also needs to go to the dedicated and talented mental health professionals for helping cognitive remediation become mainstream practice.

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INDEX

Cognitive dysfunction in mental illness

MENTAL ILLNESS AFFECTS MANY PEOPLE, but what most do not realize is that it does not just cause emotional problems – it causes cognitive problems too. The person with mental illness may find it difficult to think clearly, pay attention and remember. For some, the cognitive problems are only evident during the episodes of illness. For others, the cognitive problems are more persistent. If mental illness is managed well, the person can lead a more productive life and have longer periods of stability. To better manage an illness it is important to understand the many ways it affects functioning. When people know what the cognitive symptoms of mental illness are, they can better manage the illness and function better.

What does the word COGNITION mean?

COGNITION REFERS TO THINKING SKILLS, the intellectual skills that allow you to perceive, acquire, understand and respond to information. This includes the abilities to pay attention, remember, process information, solve problems, organize and reorganize information, communicate and act upon information. All these abilities work in a close, interdependent fashion to allow you to function in your environment.

Cognitive skills are different from academic skills. Academic skills include knowledge about different subjects like literature, math and history. Cognitive skills refer to the mental capabilities you need to learn academic subject matter, and more generally to function in daily life. Cognitive skills are the underlying skills that must be in place for you to think, read, understand, remember, plan and organize.

Some facts about cognition:

- Cognitive skills are different from academic skills
- Cognitive skills are the mental capabilities or underlying skills you need to process and learn information, to think, remember, read, understand and solve problems.
- Cognitive skills develop and change over time.
- We are born with certain cognitive capabilities - we may be better at some skills than others, but we can improve the weaker skills.
- Cognitive skills can be measured.
- Cognitive skills can be strengthened and improved.
- When cognitive skills are strong, learning becomes easier.

Let's take an example. If you are given a doctor's appointment, you need to pay attention to the secretary, understand what has been said or written, think about other appointments you have made so as to avoid a schedule conflict, remember to write down the appointment, and then remember to look at the calendar on the designated day. You also have to be able to plan how you will get to the appointment and then organize yourself to make sure you are there on time. You may even want to make notes about the things you will need to discuss at the appointment. So, to get to the doctor's appointment you need many cognitive skills: attention, language comprehension, memory, organization and planning. It can be hard to get to the appointment if these skills are not working well. Even if you are emotionally ready and willing to have the appointment, if you do not remember it you will miss it.

Why do people with mental illness have cognitive dysfunction?

Families often ask what causes the cognitive problems. Research has shown us that it is the illnesses themselves that cause much of the cognitive dysfunction. For many years people thought that the cognitive problems were secondary to other symptoms, like psychosis, lack of motivation, or unstable mood – but now we know that is not the case. Cognitive dysfunction is a primary symptom of schizophrenia and some affective disorders. That is why the cognitive problems are evident even when other symptoms are controlled – even when people are not psychotic, or in an affective episode. Furthermore, research has shown that those parts of the brain that are used for specific cognitive skills, often do not function normally in people with schizophrenia and certain affective disorders. This indicates that mental illness affects the way the brain functions, and that is what causes the cognitive problems. There are many myths about mental illness and cognitive dysfunction. Some of the most common ones are listed in the sidebar below.

Myths about cognition

- The cognitive problems will go away when the hallucinations and delusions stop.
- The cognitive problems will always go away between episodes of depression and mania.
- The cognitive problems simply reflect a lack of effort.
- The cognitive problems are all caused by medications.
- The cognitive problems are caused by being in the hospital for too long.

The ability to attend, remember and think clearly is ultimately the result of a complex interaction of factors. While it is true that mental illness often causes cognitive impairment, it is also true that other factors will affect thinking skills. Most people think best, pay attention and remember better when they are not emotionally stressed, and when they have had the opportunity to learn adaptive cognitive skills.

How does mental illness affect cognition:

What are the signs to look for?

THERE ARE DIFFERENT MENTAL ILLNESSES and they affect cognition differently. Furthermore, not every person is affected in the same way. Some people with schizophrenia have more cognitive problems than others. Some people with depression or bipolar disorder have problems in one aspect of cognitive functioning but not another. It is important to understand that a mental illness affects each person somewhat differently. By understanding all the different ways mental illnesses can affect cognition, it is easier to understand how the person you know is affected.

People who have schizophrenia often experience problems in the following aspects of cognition:

- Ability to pay attention
- Ability to remember and recall information
- Ability to process information quickly
- Ability to respond to information quickly
- Ability to think critically, plan, organize and problem solve.
- Ability to initiate speech

Truths about cognition

- Schizophrenia and many affective disorders can cause cognitive impairment.
- Careful choice and dosing of medications will avoid cognitive side effects.
- A positive attitude about learning helps people make the best use of their cognitive skills.
- A supportive and stimulating social and physical environment encourages people to cope better with their cognitive problems.
- Pre-existing and co-existing conditions can also cause cognitive impairment.

People who have affective disorders, like bipolar disorder and recurrent depressions, often experience problems in the following aspects of cognition:

- Ability to pay attention
- Ability to remember and recall information
- Ability to think critically, categorize and organize information and problem solve.
- Ability to quickly coordinate eye-hand movements

All these cognitive problems may be evident during an affective episode, but when the mood stabilizes, the problem with attention often gets better. The difficulty with memory, motor and thinking skills may continue to be evident even during periods of mood stability. When hallucinations or delusions are a feature of the illness, it is more likely that cognitive problems will be experienced. The problems with thinking skills are most often seen when alcohol and drug abuse are also present.

Who is affected by cognitive dysfunction?

Most people with schizophrenia – at least 85% – will experience problems with cognition. These problems may be evident even before psychotic symptoms start, and they may lead to a decline in academic or work performance. One of the earliest cognitive symptoms of schizophrenia is poor attention, but difficulty with memory and visual motor speed may also be evident before the onset of psychotic symptoms.

How do these cognitive problems show up in daily life?

Cognitive impairment may be experienced in different ways. Let's look at how each of these cognitive problems may be manifested.

Attention

Some people report that they have difficulty paying attention when people talk and give directions. Others find it hard to concentrate on what they read, and find that they loose track of the important points, especially when reading longer passages. They may find it hard to focus on one thing when other things are happening. They may get distracted or conversely, become so involved in one thing that they fail to attend to something else that is happening. Multi-tasking, for example, answering a customer's question while operating the cash register, becomes difficult because they have to divide their attention.

Memory

The ability to remember and recall information, particularly verbal material, is often a problem. Directions may be forgotten, or the ability to recall what has been read or heard may be reduced. *(Continues, p9)*

Most people who are depressed or in an affective episode will have difficulty with attention, concentration and thinking clearly. Those people with persistent mood problems, and those who have psychotic symptoms are more likely to continue to experience cognitive problems between episodes.

Cognitive problems can affect people of all ages. There is evidence that cognitive problems are most pronounced in the early phases of schizophrenia and then for many people level off, not getting better or worse. Since schizophrenia usually starts in adolescence or young adulthood, that is the time when the most dramatic decline in cognition may be seen. However, since that is the time when psychotic symptoms like delusions and hallucinations also start, the cognitive problems may be overlooked by a family until the psychotic symptoms stabilize. For children and adolescents, a drop in school performance may be the first sign that alerts families that something is wrong.

Cognitive problems are very common in older adults with depression. Sometimes it can be difficult to sort out whether the forgetfulness is due to depression, normal aging, or another condition like dementia. The mental health professionals will ask questions and do tests to answer that question. Many people experience memory lapses as they get older, but when someone is depressed the forgetfulness is more severe.

People with mental illness who abuse drugs and alcohol are very likely to experience cognitive problems. Drug and alcohol abuse alone can impair attention, memory and thinking skills. If substance abuse is combined with mental illness the cognitive problems can be even worse.

Most people do not have trouble remembering routines they have learned, but they may find that they do not hold onto new information as well as they used to.

The ability to process and respond to information

Family may notice that response times are slower or that it takes longer to register and understand information. Speech production can also seem slower and even though it may only be half a minute, that can seem like a long time to wait for a communication when you are trying to have a conversation with someone.

Thinking skills

Critical thinking, planning, organization and problem solving are often referred to by psychologists as the executive functions, because those are the skills that help you act upon information in an adaptive way. Take the example of cooking a meal.Even if you know how to cook each dish, to actually serve a dinner you have to plan ahead to have all the ingredients, organize and manage your time so each dish is finished at the same time. You also need to be able to adapt your plans if problems arise, like the oven does not work or an ingredient or type of pan is missing. People with mental illness may seem less able to think of alternate strategies for dealing with problems that arise, or they may have difficulty coming up with a plan, or find it hard to listen critically to new information and know what is important and what is not.

Cognitive impairment: The impact on daily functioning

When people have trouble paying attention, remembering and thinking clearly, it impacts on their ability to function in the community, at school, at work and in relationships.

Community: Impairments in memory and problem solving are associated with greater problems living independently. In fact, it has been shown that for people with schizophrenia, cognitive abilities are more linked to successful independent living and quality of life than clinical symptoms. It is easy to understand that the ability to solve problems and remember verbal information is critical for negotiating transportation, home management, shopping, finances, health and psychiatric rehabilitation.

School: The school years are formative years, when the mind is developing and one's knowledge base and critical thinking skills are broadening. Unfortunately, mental illness often starts before people have finished this educational process. The problems with attention, concentration and thinking can make it very difficult to keep up with school work, and even students who once excelled may become discouraged by the lost time, or their declining grades. When students fall behind in their academics, they may start to view themselves negatively, and prefer to quit rather than keep exposing themselves to more academic failure. They also lose the opportunity to consolidate good study and learning habits, or worse, a poor learning style may develop. People with mental illness who have dropped out of school are at a disadvantage when competing for jobs yet the cognitive problems can make it difficult to complete the necessary degrees.

Work: Research has demonstrated that people with mental illness who have difficulty with memory, problem solving, processing speed, and attention are more likely to be unemployed or have a lower occupational status. In many ways this is not surprising. Critical thinking has been identified as one of the most important skills that people need to compete in the modern workforce. Yet critical thinking/problem solving is often impaired in people with persistent mental illness. The problems that can arise at work when someone has difficulty paying attention, concentrating and remembering are also obvious. Most jobs are not just rote and repetitive, but require people to remember new information or deal with changing demands. This is difficult when cognition is not working well.

Relationships: One of the things that makes personal relationships rewarding is the give and take of support, caring and concern. People want others to really listen and pay attention to them. When someone with mental illness is not able to attend to or remember what their friend is saying, their friend may feel hurt or not listened to. At work, colleagues or bosses may think the person with mental illness does not care – or is lazy – when in fact it may be that they are not cognitively able to perform. The ability to pay attention, be focused and not get distracted is important for social functioning.

Medications and cognition: Do they help or hinder?

Families are often concerned that it is the medications that are causing the cognitive problems. For many years, psychosis and affective disorders were being treated with medications that could cause side effects, like movement disorders, attention and memory problems. More recently, newer drugs have come onto the market, and these medications seem to cause fewer side effects. Some drug companies even claim that the newer medications enhance cognitive functioning. It can be confusing for family members to figure out what medications provide the best treatment with the fewest side effects. Below are some guidelines to use when thinking about medications and cognitive side effects.

- People respond to medications differently. Some people are very sensitive to side effects; others are not.
- Medications have a therapeutic range of effectiveness. Too much medication can be associated with cognitive problems. What is too much medication for one person may be too little for the next.
- Medications interact with each other. Some people have medical conditions that they treat with medication. The risk of developing cognitive side effects is greater when multiple medications are being taken.
- When people abuse alcohol and drugs, the medications will not work as well and there is a greater risk of developing cognitive side effects.
- Some medications are more likely than others to cause cognitive side effects.
- As people get older their response to medications may change. What worked at one time may not work at another, and the dosing requirements may change.
- In general, drugs act differently in older people than in younger people.
- It is important to take medications at the prescribed doses and times.
- Many medications do not cause cognitive side effects. It is however less clear whether they really help to improve cognition.

Getting medications to work for you

FINDING THE RIGHT MEDICATION, and the right dose of medication, may take some time. Medical doctors will be best able to help if you provide information about the response to the medication. This means giving information about both emotional and cognitive functioning. The following checklist provides a good guide to follow when looking at the impact of medications on cognitive functioning. It can be very helpful if family members fill this out since they may notice things that the ill person is not aware of. However, the person being prescribed the medications should also fill it out since their experience of the medications is very important.

When medications are being taken at the prescribed doses and times:

- Attention span: ☐ better ☐ same ☐ worse
- Alertness: ☐ more drowsy ☐ alert
- Memory: ☐ more forgetful ☐ remembers well
- Thinking: ☐ is confused ☐ makes sense
- Movement: ☐ lower ☐ same as usual ☐ overactive
- Motivation: ☐ no interest in doing things ☐ interested and motivated

It can be difficult to tell if a cognitive problem is a part of the illness or a side effect of the medication. For example, some medications can cause memory problems, but both psychosis and depression also cause forgetfulness.

If cognitive problems are noticed, be sure to report them to the doctor right away so he/she can decide if it is a side effect of the medication. If side effects are a problem there are different things you and your doctor can do:

- Wait to see if the side effect goes away with time
- Reduce the amount of medication
- Try a different medication

IMPORTANT:
Never change medication on your own. Finding the right medication is a complicated decision that must be made with a doctor, based on his/her thorough assessment of your medical problem

How can cognitive dysfunction be treated?

Cognitive dysfunction can be treated in three ways: (1) using remediation techniques, (2) compensatory strategies, or (3) adaptive approaches. Most experts agree that a comprehensive program of cognitive rehabilitation uses techniques from each approach.

A mental health professional, such as a neuropsychologist, psychologist, or occupational therapist, usually makes the determination of how best to treat cognitive dysfunction. The professional would create a treatment plan that delineates the methods to be used to reach specific goals during cognitive rehabilitation. The approaches to be used (remediation vs. compensation vs. adaptation) would be determined by the individual's relative strengths and weaknesses. Each approach will be discussed below with some examples.

DEFINITION:
Cognitive Rehabilitation is the practice of training techniques that facilitate improvement in targeted cognitive areas; and focus on functional outcome.

Remediation techniques

Remediation techniques are designed by professionals for the purpose of treating cognitive dysfunction. Remediation techniques include specific drills and exercises, using computerized software, paper and pencil tasks and group activities. The goal of remediation is to change an individual's situation by improving the cognitive skill that is the target of the remediation task.

In order to begin cognitive remediation, some type of initial assessment of cognitive abilities is usually obtained. The assessment may include standardized testing; clinical interviews that focus on psychosocial history; educational and vocational background; and current functioning level. A treatment plan would then follow the evaluation so that priorities and goals can be mutually established. An individualized treatment plan that is based on personal interests and strengths, in addition to deficits that are to be the focus of the remediation program, is optimal. Most cognitive remediation specialists agree that in addition to engaging in cognitive tasks that are designed to target specific skill areas, such as problem-solving skills or attention training, an individualized treatment plan must include social, emotional, affective and functional components.

Remediation techniques are quite varied. Some emphasize the use of drill and practice to isolate what is impaired and correct it. Others rely on extensive testing both to identify the specific deficits for remediation and measure treatment effectiveness. Some focus on everyday problems and overall disability, not just specific cognitive impairments. Holistic approaches do

not separate cognitive, psychiatric, functional and affective aspects of an individual's performance. Rather, a holistic approach integrates cognitive remediation with all aspects of an individual's goals for recovery.

One example of a holistic model for cognitive remediation is the Neuropsychological Educational Approach to Rehabilitation (NEAR). This model includes computer-assisted learning and group treatment within the framework of a psychiatric rehabilitation setting. The goals of the NEAR Model include the following:

- improve neuropsychological functions
- promote awareness about learning style
- promote optimal cognitive functioning
- promote awareness of social-emotional context
- provide positive learning experiences
- promote independent learning skills
- promote confidence and competence
- provide opportunities to increase intrinsic motivation

An individual engaged in cognitive remediation using the NEAR Model would be offered individualized computer-assisted learning sessions several times a week (e.g. lasting from 30 min. to 1 hour), supportive group counseling with other individuals that share experiences about cognitive difficulties and who are engaged in cognitive remediation treatment, and specific group activities that accommodate a range of cognitive functioning and relate to rehabilitation goals (e.g. selected work tasks). The goal of the therapist is to select various learning experiences for an individual, provide the necessary objects in the environment, judge readiness to move on to learning more advanced levels and to provide support, encouragement and reinforcement.

There are different types of approaches that are being used for cognitive remediation. Each one may emphasize different activities, intensity of the intervention, or therapeutic styles. However, it helps to remember that there are several markers of a good cognitive remediation program.

1. **They do not make promises or offer quick solutions.** Most remediation is slow, time-intensive, and the outcome is related to the type of cognitive problem, prior levels of cognition, and multiple factors that may mitigate change (e. g. use of alcohol or drugs).
2. **They do not focus on the cognitive task alone.** Most remediation is best-suited to a collaborative process in which a professional guides the individual, monitors progress and is involved in ongoing and dynamic assessment of cognitive changes.
3. **They focus on skills rather than the illness.** Most remediation efforts need to take the bigger picture of how cognition relates to daily functioning into account. Good cognitive remediation understands that

improved cognition on specific tasks must generalize into daily life. That is, a computerized graph indicating a steady slope of improvement on an attention task is not sufficient. However, being attentive during social discourse is a step forward in social relatedness.

Compensatory strategies

Compensation strategies rely on trade-offs. Compensation assumes that there are alternate methods to perform a task. In other words, compensation accounts for different approaches to accomplish the same goal. For example, if a person is going shopping and cannot remember the 5 items they were asked to purchase, you might say they have poor verbal memory. If that person was able to sort the 5 items into categories, such as dairy, snacks and pet food which helped them to then remember that the shopping list was comprised of milk, yogurt, potato chips, soda and cat litter, you might say they used a mnemonic strategy that relied on organization to compensate for the lack of memory.

Compensation strategies may come 'naturally' to those who do not experience cognitive dysfunction. That is, many individuals find out how to do things using one's strengths in order to compensate for one's weaknesses. An individual with cognitive dysfunction may not have the flexibility to see things from different perspectives or shift ideas on how to do things. They may not 'naturally' alter the course of their behavior to suit cognitive abilities. Therefore, compensatory strategies may need to be taught to individuals with cognitive dysfunction.

When teaching compensatory strategies to an individual, the goal is to strive for efficiency so that the least amount of effort is expended. Many individuals with cognitive dysfunction have limited resources to process information and do not respond well to increased demands for performance. One needs to look for the simplest and most direct route to accomplish a goal, one with minimal effort and minimal demands.

Observing an individual's behavior over time and analyzing the methods they use to perform tasks are useful when investigating compensatory strategies. Understanding individual learning styles and preferences is useful when designing compensatory strategies.

Adaptive approaches

Adaptive approaches refer to changes in the environment rather than the individual. Adaptive approaches assume that remediation may not be possible, and compensation is not probable. Adaptive approaches include prosthetic devices, memory aids, and utilization of human and nonhuman resources. For example, an individual who knows they will never be able to remember all the items for a weekend's

'to-do' list may keep a micro cassette recorder on hand and dictate each item as it occurs so that it can be retrieved at the right time.

Family members may find that they adapt themselves to an individual's cognitive dysfunction by acting on behalf of the person. This type of adaptation fosters dependence. This is not an ideal adaptive approach. It can lead to caregiver burden, frustration and eventual resentment and burnout.

For example, a son living at home leaves his dirty clothes strewn about his room, ashtrays overflowing and appliances left on. A parent instructed in adaptive aids learns that the hamper cannot be behind a closed door in order to be effective. Two new, see through plastic containers, one for colored clothes and one for towels and whites, placed outside the closet are ideally situated. A commercial size, standing ashtray with safety features replaced the overflowing one on the dresser. Timers that were set for the clock radio, lights and fans were effective when incessant reminders had repeatedly failed.

Adaptive aids may be supplied on a temporary basis or permanent basis. They frequently make a significant difference for an individual with severe cognitive dysfunction to function independently.

What is a learning style?

PEOPLE APPROACH LEARNING DIFFERENTLY. Everyone has their learning style – their unique way of taking in, processing, organizing and learning information. A preferred learning style refers to the strategies we rely on to learn most quickly and effectively. It is important to recognize one's learning style preference and to know what learning strategies work best for each person. That way a person can more easily learn, remember, do their work and get along with others.

Why it is important to know your learning style

When you know how you learn best:

- There is a good fit between your cognitive strengths and your learning style.
- You learn more easily.
- You will develop more effective communication with others.
- You will build self-esteem and confidence.
- You will build better relationships with others
- You will identify work and living environments that are most compatible with your preferences.
- You will find that learning is fun.

Some different learning preferences are based on:

Sensory style: People use all their senses to learn but some prefer to learn by listening – while others are more visual, or more hands on/tactile.

Sleep habits: Everyone learns best when they are rested – the question is when are they the most rested and alert? Some people like to wake up early and do their work in the morning. Others seem to wake up at night and learn best in the evening.

Organizational style: Some people like to gather the facts and details first and then they develop the bigger picture of their goals. Others like to understand the big picture first, and once they understand the goals they think about the steps to take to meet those goals.

Social learning style: Most learning does not occur in social isolation, usually one interacts with others, perhaps the teacher or other students, a boss or colleagues. Your personality style and social preferences will affect how you learn in these situations. For example, some people need to appear competent and in charge, for others it is important to be seen as useful and helpful. Some people want to learn very independently, others like to get considerable guidance before trying something on their own. These needs influence how well people learn in different situations.

How to get to know your learning style

IT TAKES TIME TO GET TO KNOW YOUR LEARNING STYLE but there are some questions you can ask yourself to start the process. The checklist on the next page is not intended to provide a comprehensive assessment of your learning style. Rather it is there to start you thinking about your approach to learning. If you are working with teachers and specialists, they can talk to you more about your unique approach to learning. There are also learning style inventories that you can take on line. One company that offers free learning style inventories is: Performance Learning Systems, Inc. Their web site is: http://www.plsweb.com.

Families and friends help

HELP YOUR FAMILY MEMBER OR FRIEND find their particular learning style by talking to them about the checklist. Then, if it becomes clear that they learn best when information is presented in a certain way, remember to make an effort to accommodate those needs. If they are a visual learner, provide visual aids. If they are an afternoon learner, don't give the important information when they first wake up in the morning-wait until later in the day.

Learning style checklist

- ☐ I learn best in the morning
- ☐ I learn best in the afternoon.
- ☐ I learn best at night.
- ☐ I learn best by listening.
- ☐ I learn best by reading or seeing what has to be done.
- ☐ I learn best by doing- actually trying out what has to be done.
- ☐ I like to learn by being shown what to do
- ☐ I like to learn by myself- without help from others
- ☐ I am a detail oriented person.
- ☐ I do not like to be bothered with details – just give me the big picture.
- ☐ I like to work with my hands.
- ☐ I like to think and develop new ideas.
- ☐ I like quiet to think.
- ☐ I like people and activity around me when I think.
- ☐ I like regular and predictable routines.
- ☐ I like to know exactly what I have to do.
- ☐ I like lots of freedom to be creative.

After you complete this checklist, look at your answers and think about your preferences. Then think about whether you are putting yourself in learning situations that suit your preferences.

What can family members do to help improve memory?

Memory problems may be present if you notice your family member having difficulties with some of the following items.

(Use this list as a checklist for your family member.)

- ☐ forgets to take medications as prescribed
- ☐ takes too much medication
- ☐ does not keep scheduled appointments
- ☐ does not follow through on a plan they have
- ☐ cannot find items around the house
- ☐ loses track of money that is spent
- ☐ needs reminders about important dates (birthdays, anniversaries, holidays)
- ☐ repeats questions over and over
- ☐ has difficulty traveling around
- ☐ cannot remember directions or instructions
- ☐ does not learn new information easily
- ☐ forgets peoples' names
- ☐ does not remember current events
- ☐ forgets familiar procedures

Please remember:

- ◆ While the checklist above may be a useful tool for identifying the kinds of problems an individual may be experiencing, it might also be used to identify the particular strengths an individual has.
- ◆ Recognizing strengths (i.e. what an individual is capable of doing well) with praise and positive reinforcement is an important intervention.
- ◆ Offering support and encouragement is very therapeutic when working with individuals who are discouraged and overwhelmed by the many difficulties encountered in day-to-day living.

Overall guidelines for helping someone with memory problems

1. **Repeat instructions.** Become a 'broken record' without 'talking down', nagging or getting into power struggles. It is not always easy to admit you cannot remember something. No one likes to be 'wrong'.
2. **Ask an individual to repeat or paraphrase what you just told them.** Allow for errors. Offer assistance with details. Focus on the information that was recalled appropriately. Repeat as needed. Recognizing information is easier than recalling information, so give an individual choices and cues to help them remember the essential information.
3. **Put things in writing when possible.** Relying on auditory information is fraught with difficulties for people with poor memory. If the person writes down what you say, review it before assuming they wrote down the information correctly.
4. **Review plans in a consistent manner.** Systematic approaches and routines allow an individual to practice what they have learned. Remembering how to do things can improve over time with repetition.
5. **Memory is difficult to remediate, so memory aids are frequently useful.** Calendars, diaries, pill containers, watches that beep, sticky notepaper, are all useful tools to improve memory.

Specific examples and exercises to help an individual with memory problems

Narrative Case

Mary is a 33-year-old woman who has 2 years of college education. She has the diagnosis of schizophrenia and is being treated with Risperidone 4 mg. day. Her first hospitalization occurred when she was 20 years old. She has had 5 hospitalizations, has lived in 3 community residences, and does not want to live in an adult home that was recently recommended. She goes to a Continuing Day Treatment Program 3 days a week. Her goal is to volunteer at the local library. She currently lives at home with her parents who are members of a local NAMI-Family group. They have begun to address their frustration and lack of information about some of the problems they observe. They particularly notice that Mary has trouble getting up in the morning, does not seem motivated to take care of herself, forgets her doctor's appointments, needs reminders to take her medications, seems forgetful, doesn't talk very much, and is very aware that she does not think as well as she did before her illness began. Mary wants to improve her concentration and memory. She likes to attend a group that just started in her treatment program called, "Laughing and Learning", that focuses on social interaction and games to increase interaction and information processing. Mary had some cognitive testing at her day center. It was noted that she had difficulty remembering verbal information, as well as problems remembering sequences.

Recommendations

Mary's goal is to become more independent in daily living so that she can progress to a volunteer position in the community as a librarian assistant.

- She could benefit from keeping a daily diary. She and her therapist constructed the diary. There are several check-off lists that are reproduced for each day. In the evening, she has been asked to review her notes for the next day. She would see a list of reminders for the next day, including times to set her alarm clock, preparation of sticky papers to put on her bathroom mirror that cue her to shower, brush her teeth, comb her hair, and take her medication from her pillbox. These adaptive aids allow her to do her ADLs without needing verbal reminders from her parents. She is also using an alarm watch to cue her to look at the diary.
- At her day center, she has been coached to repeat verbal statements when someone is giving her directions or instructions. By repeating the verbal phrases and getting confirmation, she is increasing her ability to encode verbal information and remember details accurately. She knows that this is important for getting ready to work as a volunteer in the library. This compensatory technique of repeating what others say also helps her social interactions with others since she appears interested in what they are saying.
- She has begun to work on computer tasks at home with her younger brother. They look at ways to use the Internet to find information. She is learning new procedures for problem solving as she remembers commands and sequences of information and she feels proud of her accomplishments. This computer activity is a remediation technique for problem solving skills.

What can family members do to help improve attention?

Problems with attention may be present if you notice your family member having difficulties with some of the following items.

(Use this list as a checklist for your family member.)

- ☐ seems confused or absent-minded
- ☐ seems indifferent to the environment
- ☐ loses track of time
- ☐ cannot concentrate or understand what is read
- ☐ cannot participate in a conversation
- ☐ interrupts others when they are talking
- ☐ cannot remember what they just said to someone
- ☐ gets distracted in the middle of things
- ☐ frequently says, "I'm bored"
- ☐ tries to do too many things simultaneously
- ☐ gets easily overwhelmed
- ☐ wanders around in an aimless manner

Please remember:

- ◆ While the checklist above may be a useful tool for identifying the kinds of problems an individual may be experiencing, it might also be used to identify the particular strengths an individual has.
- ◆ Recognizing strengths (i.e. what an individual is capable of doing well) with praise and positive reinforcement is an important intervention.
- ◆ Offering support and encouragement is very therapeutic when working with individuals who are discouraged and overwhelmed by the many difficulties encountered in day-to-day living.

Overall guidelines for helping someone with problems with attention

1. **Limit information to the span of attention.** Keep things simple, direct, short and to the point.
2. **Don't expect someone to be able to do multiple tasks at the same time.** Divided attention is extremely difficult especially with increased task complexity.
3. **Regulate the tone, volume and rhythm of speech.** If you want someone to be interested, sound interesting. Enthusiasm easily captures attention.
4. **Be aware of the need for rest.** Respect the limits of poor endurance.
5. **The more interesting and personally involved an individual can become in a task, the greater the attention.** Find out what 'holds' someone's attention.
6. **Direct eye contact and sense of touch, when comfortable and appropriate, can be used to get someone's attention and to sustain involvement.**
7. **Be aware of distractions (e.g. extraneous or background noises, multiple speakers, poor acoustics, disorganized surroundings, complex visual patterns) and attempt to simply the environment.** (Conversely, when someone pays attention with more stimulation, provide sensory feedback - rocking chairs, rubber stress balls to squeeze, background music.)
8. **Provide a balance of activities across physical, mental and social domains.**

Specific examples and exercises to help an individual with problems with attention

Narrative Case

Peter is a 25 year old man who likes to visit his parents for long weekends. He has been living in a supportive residence and is doing well in his recovery and rehabilitation since his discharge from the hospital for major depression and drug use. During a recent visit home, his parents noticed that he was restless and unable to sit at the table during the usual after dinner conversation. He would leave the room and watch TV but when asked what he was watching he said he was unable to follow the story. When everyone tried to join him in the living room, he would go outside and sit on the porch. His parents reported back to his case manager that Peter was distant, preoccupied and they worried about a relapse. The case manager noted that his restlessness has been associated with distractibility and limited attention span. Peter went back to his residence and felt distressed because he couldn't converse with his family and felt sad that he is disappointing them.

Recommendations

Given Peter's distractibility and withdrawal from conversation, the family has been asked to consider alternative ways of engaging together as a family unit.

- Consult with Peter's psychiatrist to see if a medication adjustment is necessary since the apparent distractibility and inattention may be accounted for by medication side-effects (e.g. restlessness, akathisia).
- Peter will be asked to clear the table immediately following dinner with his sister. The short-term goal and concreteness of the task that doesn't depend on following a conversation allows Peter to feel that he is still a part of the after dinner ritual.
- The family remembered that Peter loves jigsaw puzzles. They have purchased a scene of the Canadian Rockies that reminded them of a favorite vacation spot and have set a goal to complete the puzzle and assemble old photos into family albums. Peter is able to sustain his attention for up to 15 minutes at a time. He can take frequent rest periods and alternate tasks and usually has someone to work with on the joint projects throughout the weekend that he is home.
- Each family member was 'assigned' a 1:1 time for a brief conversation with Peter. His focus is best when he does not have the over- stimulation of several people conversing at the same time. In fact, he has discovered some favorite locations for the respective conversations: on the porch with mom while sitting in the swing; on the basketball court with his brother; in the kitchen with his dad while clearing dishes; and in the laundry room with sister.

What can family members do to help improve critical thinking skills?

Difficulties with critical thinking skills (related to reasoning, analytical thinking, problem solving) may be present if you notice your family member having difficulties with some of the following items.

(Use this list as a checklist for your family member.)

- ☐ responds too quickly, impulsively
- ☐ does not seem to understand consequences of actions
- ☐ repeat mistakes without apparent learning from previous errors
- ☐ has trouble getting things started independently
- ☐ does not like to have routines change
- ☐ has trouble adjusting to new demands
- ☐ experiences difficulties with surprises or unexpected events
- ☐ does not like to make decisions
- ☐ never plans ahead
- ☐ seems indifferent to figuring out practical problems
- ☐ immediately asks for assistance
- ☐ does not like to ask for help even when having difficulty
- ☐ does things in disorderly or disorganized manner
- ☐ frequently does not finish what is started
- ☐ appears "lazy" and poorly motivated to figure things out
- ☐ becomes rigid and concrete when errors are pointed out
- ☐ does not evaluate actions that may be dangerous
- ☐ cannot see one's own mistakes
- ☐ does not seek out alternatives or options

Please remember:

- While the checklist above may be a useful tool for identifying the kinds of problems an individual may be experiencing, it might also be used to identify the particular strengths an individual has.
- Recognizing strengths (i. e. what an individual is capable of doing well) with praise and positive reinforcement is an important intervention.
- Offering support and encouragement is very therapeutic when working with individuals who are discouraged and overwhelmed by the many difficulties encountered in day-to-day living.

Overall guidelines for helping someone with difficulties with critical thinking

1. **Understand the need for routines, systematic procedures, organization and structure.** Provide supervision as needed, especially when judgment is needed for safety.
2. **Develop acronyms or short commands to eliminate impulsive actions.** "STOP!" "SOS". "HELP". Attempt to make these cues automatic triggers to evaluate the situation at hand fully before any action is taken.
3. **Provide encouragement and praise for actions that are initiated or maintained and followed-through by individuals who have trouble getting started or don't complete tasks.**
4. **Offer guiding questions ("what's the first step?"; "how would you begin?"; "what do you think?") instead of ready-made answers for individuals who become overly dependent on assistance or lack confidence in decision-making.**
6. **Demonstrate procedures and sequences to elicit awareness about steps taken during everyday problem solving.**
7. **Use self-talk by verbalizing out loud.** "Metacognition", thinking about your thinking, helps to improve feedback and connections between thoughts and actions.
8. **Don't make assumptions about how an individual can perform daily tasks without asking how they would solve the problem or observing the actual performance.**

Specific examples and exercises to help an individual with difficulties with critical thinking

Narrative Case

Mitchell is 43 years old and has not had a hospitalization for 15 years. His schizophrenia is well treated, but he continues to have residual negative symptoms, is notably unable to plan activities and has poor daily problem-solving skills. He does not have any friends, but continues to visit his brother's family on a weekly basis. Mitchell has been unsuccessful in returning to supported employment, which he continues to express interest in, and has been consistent in his attendance at a psychosocial club. Feedback from his job coach notes that he is fixed in the way that he approaches tasks and cannot ask for help. Mitchell is a resident in a supervised apartment program and has a roommate. Everyone agrees that Mitchell has been persistent and motivated to improve his skills. He acknowledges that he is unable to grasp how to go about making things happen in his day-to-day life and wants to become more flexible in his thinking.

Recommendations

Mitchell will benefit from trying new activities to improve his thinking skills, especially in the areas of problem solving, cognitive flexibility and making decisions.

- Mitchell will be asked to play card games with his roommate, such as Gin Rummy, Solitaire, UNO and a problem-solving card game called SET, in order to practice applying set rules in different situations. He also expressed interest in learning how to play backgammon, a game that his roommate knows. In order to learn the game, he will need to begin to feel more comfortable asking for assistance and guidance. His incentive is to learn how to play chess, which he knows is more difficult than backgammon. He understands that these recreational pursuits are associated with his vocational goals.
- Mitchell's brother has been asked to work with him on the computer. They have purchased the educational software package, "Where in the USA is Carmen SanDiego?" and "Where in the World is Carmen SanDiego?" Mitchell will be asked to work on the tasks that require him to use reasoning skills to solve a detective case. The repetition of procedures provides comfort, but Mitchell is learning how to build on what he knows and apply his skills to new situations. Another interesting aspect of this activity is that it models how to ask for information from multiple strangers.
- At the psychosocial club, Mitchell has begun to focus on his budgeting skills. He is learning how to make a plan, monitor his spending and evaluate his effectiveness in wanting to save money for his own computer.
- Mitchell has been able to enjoy himself more and to express his pleasure – something that his negative symptoms have dampened for years. He has been offered an opportunity to begin to write articles for the clubhouse newsletter. This will help organize his thoughts as he plans

what he wants to write about for each issue. He has also been asked to consider working on computers at the clubhouse. He agrees that it is an opportunity to socialize while he shares his newfound competence with his peers.

- Consult with Mitchell's job coach prior to his being assigned to a new worksite. Several adjustments and adaptations of the work setting and work tasks may be beneficial and better suited to his strengths and deficits so that he can reach optimal performance.

Common questions that families ask about cognitive dysfunction in mental illness

Are cognitive deficits caused by the medications that my family members are taking?

Many individuals receiving neuroleptics (antipsychotic medication) will repeatedly focus on medications as being the causative agent for cognitive dysfunction. Most of the time, this may not be the case. Cognitive deficits are frequently a symptom of the illness. There are however, some exceptions. For example, anticholinergic medications, such as Cogentin, given for side-effects of typical neuroleptics (e.g. Haldol, Prolixin), may impair memory functions. While this may be the case, stopping medications is usually not an optimum response. The trade-off of recurring positive symptoms (e.g. hallucinations, delusions) when medications are terminated would not offset the small gain in improved cognition. All individuals need to continue to work with their psychopharmacologist or treating psychiatrist when evaluating the medication regimen, stopping or switching medications, or optimizing the specific medication plan.

Can medications improve cognition?

There is much attention focused on the newer atypical neuroleptics, such as Clozapine, Olanzapine, Risperidone, Ziprasidone, Quetiapine, and whether or not they are effective in "improving" cognition. Currently, there are no dramatic or consistent results that any one medication has the power to increase cognitive skills to the level of normal functioning. There are, however, some studies that suggest that some of the newer neuroleptics may provide minimal benefits in certain specific areas of cognition. This research is ongoing and definitive results and comparisons of medications with each other will continue to be a focus of attention. In addition, adjunctive medications or additional agents that are specifically aimed at improving cognition have been targeted for development and future investigation, because the needs are so apparent.

Will my family member regain their thinking abilities and academic skills and return to their previous level of functioning?

Each person is unique and has patterns of functioning related to cognitive development that occurred prior to the onset of serious mental illness. Typically, a family member is overwhelmed when an individual who was a good student during high school now exhibits compromised functioning and cognitive decline. These are individuals with many strengths that may remain intact and that need to be rediscovered (e.g. use of vocabulary, general knowledge and fund of information). The individual may continue to feel competent while using these cognitive skills in word games, such as Scrabble, or activities that focus on factual information, such as Trivial Pursuit or Jeopardy. Certainly, an individual with above average intellect or academic background will have a foundation to draw upon. On the other hand, discouragement and disappointment regarding current difficulties need to be handled with compassion and encouragement to motivate the individual to work on realistic goals and efforts to continue to address residual deficits and areas of weakness.

How are negative symptoms of schizophrenia related to cognitive dysfunction?

Negative symptoms relate to difficulties with communication, known as 'alogia' (i.e. not having much to say); difficulties expressing emotions, or 'affective flattening' (i.e. lack of facial expression and emotional spontaneity); difficulties with planning and doing activities, known as 'avolition' (i.e. problems with motivation and doing things on one's own, especially without structure); and difficulties with experiencing pleasure, known as 'anhedonia' (i.e. little experience of enjoyment). Frequently, individuals with prominent negative symptoms also seem to have cognitive dysfunction. While they appear to be independent of each other, together they seem to add to the individual's poor social, community and vocational functioning.

Where can my family member receive treatment that focuses on cognitive deficits?

More professionals are becoming aware of the need for treatment that addresses the cognitive deficits of individuals with chronic mental illness. There is an increase in research efforts and training for practitioners who want to learn specific techniques for cognitive remediation. In fact, research in this area is quickly contributing to the application of the best practices of psychiatric rehabilitation. Inpatient and outpatient treatment programs are beginning to adopt the practice of cognitive remediation, in a variety of ways, from individualized treatment planning that incorporates cognitive strengths and weaknesses, to computerized assisted learning programs, to group modalities that incorporate systematic principles of remediation, compensation and adaptation. If you contact resources in your area, you may be able to find professionals who provide evaluations and treatment of cognitive dysfunction. Becoming a family advocate in your region will help the progression towards wider availability of this important treatment.

Resources for families

Institutional resources

FEGS

315 Hudson Street
New York, New York 10013
Contact: Ellen Stoller
212-366-8038

This agency has an ongoing cognitive remediation program as part of their Intensive Psychiatric Treatment Programs and Continuing Day Treatment at various sites. Cognitive remediation services are integrated into an individual's rehabilitation goals (e. g. living, socializing, learning, working). It is an exemplary treatment center for state of the art rehabilitation technology.

CUCS

120 Wall Street, 25th floor
New York, New York 10015
Contact: Andrea White
212-801-3300

This agency recognizes the need to integrate cognitive remediation into the support services they provide for mentally ill and chemically dependent individuals who are homeless. They have a well established Learning Center which provides an exemplary setting for the treatment of cognitive problems.

The Family Resource Center

Located in the library of the Nathan Kline Institute for Psychiatric Research,140 Old Orangeburg Road, Orangeburg, New York 10962, telephone #845-398-6576, Stuart Moss, MLS, Library Director

The resources include books by and about individuals with serious mental illness, videotapes, reference guides and staff who are willing to assist family members.

Call to arrange times to visit.

Conferences

Cognitive Remediation in Psychiatry

An annual conference cosponsored by Montefiore Medical Center, Institute of Living, Kessel Foundation, FEGS that convenes the first Friday in June. Well-known experts share research findings and clinical practices from a variety of perspectives. Contact amedalia@aol.com to be placed on the mailing list for the next conference.

Books

Christine Adamec (1996). *How to live with a mentally ill person: a handbook of day-to-day strategies.* New York: John Wiley & Sons.

A mother of a daughter with schizophrenia shares strategies that have been useful. Topics include ways to support medication compliance, financial aspects of medical care, and communication with health care professionals and tips for self-care for caregivers.

Xavier Amador (with Anna-Lisa Johanson). (2000). *I am not sick, I don't need help!: helping the seriously mentally ill accept treatment: a practical guide for families and therapists*. Peconic, NY: Vida Press.

Individuals with cognitive deficits may lack self-awareness and insight. This book deals with tough issues in a practical way.

Charles A. Kaufman and Jack M. Gorman (eds.) (1996). *Schizophrenia: new directions for clinical research and treatment.* Larchmont, NY.

A compendium of articles written by members of Columbia University's Clinical Psychology and Psychiatry Departments that covers brain physiology, etiology of the illness, and the impact of the illness on the individual, the family and society.

Irene S. Levine and Stuart Moss (September 2000). *Mental Health Resources on the Web for Families.* Published by the Nathan Kline Institute for Psychiatric Research.

An overview of the Internet and how to access up-to-date resources on the web. This reference guide lists important website addresses and how-to's for searching and evaluation of sources.

Diane T. Marsh and Rex M. Dickens (1997) *Troubled journey: coming to terms with the mental illness of a sibling or parent.* New York, NY: Jeremy P. Tarcher/Putnam.

Reviews issues related to disruptions in the life cycle of a family related to coping with a seriously mentally ill family member. Many first-person examples are shared.

Alice Medalia, Nadine Revheim and Tiffany Herlands (2002) *Remedition of Cognitive Deficits in Psychiatric Patients: A Clinician's Manual* New York: Montefiore Medical Center.

A "how to" manual that very clearly describes how to set up and run a cognitive remediation program for people with psychiatric disorders. It is intended for trained mental health clinicians who want to learn how to provide cognitive remediation services.

Bert Pepper and Hilary Ryglewicz (1996.) *Lives at risk: understanding and treating young people with dual disorders.* New York: Free Press.

This book addresses a group of individuals who struggle with substance abuse and/or personality disorders in addition to the problems of serious mental illness from a biopsychosocial perspective. An excellent resource for dealing with multiple complex issues, including "transinstitutionalization" (e. g. from hospital setting to jails and prisons).

E. Fuller Torrey. (1995). *Surviving schizophrenia: a manual for families, consumers, and providers.* New York, NY: Harper Perennial (3rd ed.).

This is the "standard" reference book on schizophrenia that describes causes, symptoms, treatment and course of the illness. Focuses on education, advocacy and proactive concerns for the individual with the illness as well as for the family.

Peter J. Weiden, Patricia L. Scheifler, Ronald J. Diamond, and Ruth Ross. (1999). *Breakthroughs in antipsychotic medications: a guide for consumers, families, and clinicians.* New York, NY: W. W. Norton & Co.

An excellent reference that describes what medications do and how, reviews technical aspects of multiple medications, including new atypical antipsychotics, discusses side-effects, risks and benefits of switching medications, optimizing medication regimens and dealing with noncompliance issues. Includes a comprehensive glossary of specific terms to enhance understanding of psychiatric jargon.

Newsletters

Mental Health Recovery Newsletter

PO Box 301 W. Dummerston, VT 05357
802-254-2092 (phone)
802-257-7499 (fax)
Copeland@mentalhealthrecovery.com
www.mentalhealthrecover.com

This free, quarterly newsletter, published by Mary Ellen Copeland, MS, MA, is designed for those who want more information about recovering from disabling psychiatric conditions. Known for her Wellness Recovery Action Plan (WRAP) workbooks for people with depression and manic depression, workshops and training for Recovery Educators, CD-ROMs, and videos, Ms. Copeland provides inspiration and structured self-help activities for coping with psychiatric symptoms on a daily basis.

NARSAD Research Newsletter

The National Alliance for Research on Schizophrenia and Depression
NARSAD Research Fund
60 Cutter Mill Road, Suite 404
Great Neck, NY 11021
1-800-829-8289
www.narsad.org

Up-to-the-minute reporting on the latest research studies and future trends, including results of research projects supported by the organization, announcements of fundraising events, and availability of educational materials, free of charge.

Treatment Advocacy Center (TAC)
330 N. Fairfax Drive, Suite 220
Arlington, VA 22201
703-294-6001
info@psychlaws.org
www.psychlaws.org

This nonprofit organization focuses on eliminating legal or clinical barriers that interfere with timely and humane treatment for individuals with severe brain disorders who are not receiving appropriate medical care. The overall goal is to prevent the devastating consequences, such as homelessness, suicide, victimization, worsening of symptoms, violence, and incarceration, if individuals are not treated. Information about treatment laws and the benefits of medication compliance are provided. This center is affiliated with the work of E. Fuller Torrey, a longtime advocate for the mentally ill.

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Phoenix, AZ 85015-1955
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(fax) 602-335-0577
www.ilp-online.com

Selective products from this catalog may be useful adaptive aids (e. g. low vision products, a check writing guide).

Sammons/Preston
An AbilityOne Company
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Bollingbrook, IL 60440
1-800-323-5547
www.sammonspreston.com

Large selection of adaptive equipment for wide-range of disabilities and needs (e.g. medication reminders). See "Enrichments Catalogue".

Abledata
8630 Fenton Street, Suite 930
Silver Springs, MD.
1-800-227-0216
www.abledata.com

An alphabetical online listing of links to various suppliers and organizations related to individuals whose disabling conditions interfere with independent living.

Learning style inventories

Performance Learning Systems, Inc.
www.plsweb.com

Provides learning style inventories on line.

World wide web sites

National Alliance for the Mentally Ill (NAMI)
http://www.nami.org/

National Alliance for the Mentally Ill of New York State (NAMI-NYS)
http://www.naminys.org/

National Institute of Mental Health
http://www.nimh. nih. gov/

National Mental Health Consumers' Self-Help Clearinghouse
http://www.mhselfhelp.org

The Schizophrenia Home Page
http://www.schizophrenia.com

Mental Health Association of New York State
http://www.mhanys.org

Federation of Families For Children's Mental Health
http://www.ffcmh.org

Notes: