

NOTICE OF PRIVACY PRACTICES

Effective Date: April 14, 2003

THIS NOTICE DESCRIBES HOW CLINICAL INFORMATION ABOUT OUR CONSUMERS MAY BE USED AND DISCLOSED, AND HOW OUR CONSUMERS, THEIR GUARDIANS AND/OR THEIR PERSONAL REPRESENTATIVES, CAN GET ACCESS TO THIS INFORMATION. *GUARDIANS AND PERSONAL REPRESENTATIVES SHOULD BE AWARE THAT THE WORD "YOU" IN THIS NOTICE REFERS TO THE CONSUMER, NOT NECESSARILY TO THE GUARDIAN.* PLEASE REVIEW IT CAREFULLY.

Independent Living Association, Inc., ("ILA") is committed to protecting the privacy of you and your family, and sharing information about you only with those who need to know and who are permitted by law to receive this information. We are required by both federal and state law protect the privacy and confidentiality of mental hygiene information that may reveal your identity, and to provide you with a copy of this notice which describes the clinical information privacy practices of our agency, its staff, and affiliated service providers that jointly provide services for you. A copy of our current notice will always be posted in our reception area. You will also be able to obtain a copy by accessing our website at www.ILAonline.org, calling our office at (718) 852-2000, or asking for one at the time of your next visit.

If you have any questions about this notice or would like further information, please contact Ms. Lenore Meurer, Privacy Officer at (718) 852-2000.

CONFIDENTIALITY OF MENTAL HYGIENE INFORMATION

Clinical information about you may be used by ILA staff (or its business associates) in connection with our duties to provide you with treatment, to obtain payment for that treatment, or to conduct our agency's business operations.

1. We will not disclose clinical information about you **without your consent** or written authorization, except for the following purposes:
 - When we are communicating with other health care providers who are also HIPAA compliant, and are currently providing services to you, or working with us to plan for services for you, if this communication is about treatment, payment, or agency operations.
 - "treatment" means that we may share clinical information about you inside our agency, or with another agency, to plan for and provide services for you. If you agree, we may also share information about you with others outside mr/dd service system when necessary to provide other services; for example, we may disclose certain information about you to a prospective employer in connection with a job placement or training program.
 - "payment" means that we may use clinical information about you, or share it with others, so that we obtain payment for your services

- "operations" means that we may use clinical information about you, or share it with others, in order to conduct our normal business operations. For example, we may use clinical information about you to evaluate the performance of our staff in providing services to you, or to educate our staff on how to improve the care they provide for you.
- To a personal representative who is authorized to make health care decisions on your behalf;
- To government agencies or private insurance companies in order to obtain payment for services we provided to you;
- To comply with a court order;
- To appropriate persons who are able to avert a serious and imminent threat to the health or safety of you or another person;
- To appropriate government authorities to locate a missing person or conduct a criminal investigation as permitted under Federal and State confidentiality laws;
- To other licensed agency emergency services as permitted under Federal and State confidentiality laws;
- To an attorney representing you in an involuntary hospitalization or medication proceeding. (We will not disclose clinical information about you to an attorney for any other reason without your authorization, unless we are ordered to do so by a court.)
- To authorized government officials for the purpose of monitoring or evaluating the quality of care provided by the agency or its staff;
- To qualified researchers when such research poses minimal risk to your privacy;
- To coroners and medical examiners to determine cause of death; and
- If you are an inmate, to your correctional facility if they certify that the information is necessary in order to provide you with health care, or to protect the health or safety of you or any other persons at the correctional facility.

Funeral Directors. In the event of your death, we may release this information to funeral directors as necessary to carry out their duties.

Organ And Tissue Donation. In the event of your death, we may disclose your health information to organizations that procure or store organs, eyes or other tissues so that these organizations may investigate whether donation or transplantation is appropriate and possible under applicable laws. Your organs and/or tissue would not be used for transplant without written consent by a legally authorized person.

We may use or disclose clinical information about you if we have removed any information that might reveal who you are.

Emergencies Or Public Need. We may use or disclose clinical information about you in an emergency or for important public needs. For example, we may share your information with public health officials at the New York State or City health departments who are authorized to investigate and control the spread of diseases.

As Required By Law. We may use or disclose your clinical information if we are required by law to do so, or if a court orders us to do so in a lawsuit or judicial

proceeding. We also will notify you of these uses and disclosures if notice is required by law.

Victims Of Abuse, Neglect Or Domestic Violence. We may release clinical information about you to a public health authority that is authorized to receive reports of abuse, neglect or domestic violence. For example, we may report your information to government officials if we reasonably believe that you have been a victim of abuse, neglect or domestic violence. We will make every effort to obtain your permission before releasing this information, but in some cases we may be required or authorized to act without your permission.

National Security And Intelligence Activities Or Protective Services. We may disclose clinical information about you to authorized federal officials who are conducting national security and intelligence activities or providing protective services to the President or other important officials.

2. If you do not object, we may disclose information about you in the following situations:

Disclosure To Friends And Family Involved In Your Care. We will ask you whether you have any objection to sharing clinical information about you with your friends and family involved in your care.

Consumer Profile Database. For purposes other than treatment, payment and business operations. We will ask you whether you have any objection to including information about you in our consumer profile database.

3. Special Situations

- *Fund-raising.* We may use demographic information about you (such as your age, gender, where you live or work, and the dates that you received services) in order to contact you to raise money to help us operate. We may also share this information with a charitable foundation that will contact you to raise money on our behalf. If you do not want to be contacted for these fund-raising efforts, please write to Ms. Lenore Meurer, Privacy Officer c/o Independent Living Association, Inc., 110 York Street, Brooklyn, N.Y. 11201.
- *Research.* When you have agreed to participate in the research and an Institutional Review Board and Privacy Committee has approved the use of the clinical information for the research purpose. However, under some circumstances, we may use and disclose your clinical information without your authorization;
- if we obtain approval through the special process as defined above, to ensure that research without your authorization poses minimal risk to your privacy.
- if we do not allow researchers to use your name or identity publicly.
- to people who are preparing a future research project, so long as any information identifying you does not leave our facility. In the unfortunate event of your death, we may share your clinical information with people who are conducting research using the information of deceased persons, as long as they agree not to remove from our facility any information that identifies you.

WHAT INFORMATION IS PROTECTED

ILA is committed to protecting the privacy of clinical information we gather about you while providing services. Some examples of protected clinical information are:

- the fact that you are a participant at, or receiving services from, our agency;
- information about your condition;
- information about health care products or services you have received or may receive in the future (such as a medication or equipment); or
- information about your health care benefits under an insurance plan (such as whether a prescription is covered);

when combined with:

- geographic information (such as where you live or work);
- demographic information (such as your race, gender, or ethnicity);
- unique numbers that may identify you (such as your social security number, your phone number, or your Medicaid number); and
- other types of information that may identify who you are.

Incidental Disclosures. While we will take reasonable steps to safeguard the privacy of your information, certain disclosures of your information may occur during or as an unavoidable result of our otherwise permissible uses or disclosures of your information. For example, during the course of a treatment session, other consumers in the treatment area may see, or overhear discussion of, your information.

WHAT RIGHTS DO YOU HAVE

How To Access Your Clinical Information. You generally have the right to inspect and request a copy of your clinical information that is contained within your designated record set as defined by ILA. For more information, please see the section below titled "Your Rights".

How To Correct Your Clinical Information. You have the right to request that we amend your clinical information if you believe it is inaccurate or incomplete. For more information, please see the section below titled "Your Rights".

How To Keep Track Of The Ways Your Health Information Has Been Shared With Others. You have the right to receive a list from us, called an "accounting list," which provides information about when and how we have disclosed clinical information about you to outside persons or organizations, when those disclosures are not treatment, payment or business operations related. Many routine disclosures we make will not be included on this accounting list, but the accounting list will identify non-routine disclosures of your information. For more information, please see the section below titled "Your Rights".

How To Request Additional Privacy Protections. You have the right to request further restrictions on the way we use clinical information about you or share it with others. We are not required to agree to the restriction that you request, but if we do, we will be bound by our agreement. For more information, please see section below titled, "Your Rights".

How To Request More Confidential Communications. You have the right to request that we contact you in a way that is more confidential for you, such as at home instead of at work, to the extent that your request does not interfere with treatment. We will try to accommodate all reasonable requests. For more information, please see the section below titled "Your Rights".

How Someone May Act On Your Behalf. You have the right to name a personal representative who may act on your behalf to control the privacy of your clinical information. Parents and guardians will generally have the right to control the privacy of clinical information about minors or unless the minors are permitted by law to act on their own behalf. The same principle applies for guardians of adults.

- **How To Learn About Special Protections For HIV, Alcohol and Substance Abuse, And Genetic Information.** Special privacy protections apply to HIV-related information, alcohol and substance abuse treatment information, and genetic information. Some parts of this general Notice of Privacy Practices may not apply to these types of information. If your clinical records include this type of information, you will be provided with separate notices explaining how the information will be protected. To request copies of these other notices now, please contact Ms. Lenore Meurer, Privacy Officer at (718) 852-2000.
- **How To Obtain A Copy Of This Notice.** You have the right to a paper copy of this notice. You may request a paper copy at any time, even if you have previously agreed to receive this notice electronically. To do so, please call Ms. Lenore Meurer, Privacy Officer at (718) 852-2000.
- You may also obtain a copy of this notice from our website at www.ILAonline.org, or by requesting a copy at your next visit.

How To Obtain A Copy Of Revised Notice. We may change our privacy practices from time to time. If we do, we will revise this notice so you will have an accurate summary of our practices. The revised notice will apply to all of your clinical information, and we will be required by law to abide by its terms. We will post any revised notice in our agency reception area. You will also be able to obtain your own copy of the revised notice by accessing our website at www.ILAonline.org, calling our office at (718) 852-2000 or asking for one at the time of your next visit. The effective date of the notice will always be noted in the top right corner of the first page.

How To File A Complaint. If you believe your privacy rights have been violated, you may file a complaint with us or with the Secretary of the Department of Health and Human Services. To file a complaint with us, please contact Ms. Lenore Meurer, Privacy Officer at (718) 852-2000 or

write to Privacy Officer, Independent Living Association, Inc., 110 York Street, Brooklyn, N.Y. 11201. You may write to the Secretary of the Department of Health and Human Services, 200 Independence Avenue, S.W., HHH Building Room 509H, Washington DC, 20201 or by calling them at (877) 696-6775. You may file a grievance with the Office of Civil Rights by calling them at (866) OCR-PRIV; or (866) 627-7748; or (TTY) (866) 788-4989; or by e-mail www.hhs.gov/ocr. *No one will retaliate or take action against you for filing a complaint.*

HOW YOU CAN EXERCISE YOUR RIGHTS TO ACCESS AND CONTROL OF YOUR CLINICAL INFORMATION

We want you to know that you have the following rights to access and control your clinical information. These rights are important because they will help you make sure that the clinical information we have about you is accurate. They may also help you control the way we use your information and share it with others, or the way we communicate with you about your medical matters.

1. Right To Inspect And Copy Records

- You have the right to inspect and obtain a copy of any clinical information contained within your designated record set that may be used to make decisions about you and your treatment for as long as we maintain this information in our records. This includes medical, clinical and billing records. To inspect or obtain a copy of your clinical information, please submit your request in writing to Ms. Lenore Meurer, Privacy Officer c/o Independent Living Association, Inc., 110 York Street, Brooklyn, N.Y. 11201.

If you request a copy of the information, we may charge a fee for the costs of copying, mailing or other supplies we use to fulfill your request. The standard fee is \$0.75 per page and must generally be paid before or at the time we give the copies to you.

We will respond to your request for inspection of records within 10 days. We ordinarily will respond to requests for copies within 30 days if the information is located in our facility, and within 60 days if it is located off-site at another facility. If we need additional time to respond to a request for copies, we will notify you in writing within the time frame above to explain the reason for the delay and when you can expect to have a final answer to your request.

Under certain very limited circumstances, we may deny your request to inspect or obtain a copy of your information. If we do, we will provide you with a summary of the information instead. We will also provide a written notice that explains our reasons for providing only a summary, and a complete description of your rights to have that decision reviewed and how you can exercise those rights. The notice will also include information on how to file a complaint about these issues with us or with the Secretary of the Department of Health and Human Services. If we have reason to deny only part of your request, we will provide complete access to the remaining parts after excluding the information we cannot let you inspect or copy.

2. Right To Request Amendment of Records

- If you believe that the clinical information we have about you is incorrect or incomplete, you may ask us to amend the information. You have the right to request an amendment for as long as the information is kept in our records. To request an amendment, please write to Ms. Lenore Meurer, Privacy Officer c/o Independent Living Association, Inc., 110 York Street, Brooklyn, N.Y. 11201.

Your request should include the reasons why you think we should make the amendment. Ordinarily we will respond to your request within 60 days. If we need additional time to respond, we will notify you in writing within 60 days to explain the reason for the delay and when you can expect to have a final answer to your request.

If we deny part or all of your request, we will provide a written notice that explains our reasons for doing so. You will have the right to have certain information related to your requested amendment included in your records. For example, if you disagree with our decision, you will have an opportunity to submit a statement explaining your disagreement which we will include in your records. We will also include information on how to file a complaint with us or with the Secretary of the Department of Health and Human Services. These procedures will be explained in more detail in any written denial notice we send you.

3. Right To An Accounting Of Disclosures

After April 14, 2003, you have a right to request an “accounting of disclosures” which is a list that contains certain information about how we have shared your information with others. An accounting list, however, **will not** include any information about:

Disclosures we made to you;

Disclosures we made pursuant to your authorization;

Disclosures we made for treatment, payment or health care operations;

Disclosures made to your friends and family, as you have authorized, who are involved in your care or payment for your care;

Disclosures made to federal officials for national security and intelligence activities;

Disclosures that were incidental to permissible uses and disclosures of your clinical information;

Disclosures for purposes of research, public health or our normal business operations of limited portions of your clinical information that do not directly identify you;

Disclosures about inmates to correctional institutions or law enforcement officers;

Disclosures made before April 14, 2003.

To request this accounting list, please write to Ms. Lenore Meurer, Privacy Officer c/o Independent Living Association, Inc., 110 York Street, Brooklyn, N.Y. 11201. Your request must state a time period within the past six years (but after April 14, 2003) for the disclosures you want us to include. For example, you may request a list of the disclosures that we made between January 1, 2004 and January 1, 2005. You have a right to receive one accounting list within every 12 month period for free. However, we may charge you for the cost of providing any

additional accounting list in that same 12 month period. We will always notify you of any cost involved so that you may choose to withdraw or modify your request before any costs are incurred.

Ordinarily we will respond to your request for an accounting list within 60 days. If we need additional time to prepare the accounting list you have requested, we will notify you in writing about the reason for the delay and the date when you can expect to receive the accounting list. In rare cases, we may have to delay providing you with the accounting list without notifying you because a law enforcement official or government agency has asked us to do so.

4. Right To Request Additional Privacy Protections

- You have the right to request that we further restrict the way we use and disclose your clinical information to treat your condition, collect payment for that treatment, or run our agency's normal business operations. You may also request that we limit how we disclose information about you to family or friends involved in your care. For example, you could request that we not disclose information about a surgery you had. To request restrictions, please write to Ms. Lenore Meurer, Privacy Officer c/o Independent Living Association, Inc., 110 York Street, Brooklyn, N.Y. 11201. Your request should include (1) what information you want to limit; (2) whether you want to limit how we use the information, how we share it with others, or both; and (3) to whom you want the limits to apply.

We are not required to agree to your request for a restriction, and in some cases the restriction you request may not be permitted under law. *However, if we do agree, we will be bound by our agreement unless the information is needed to provide you with emergency treatment or comply with the law.* Once we have agreed to a restriction, you have the right to revoke the restriction at any time. Under some circumstances, we will also have the right to revoke the restriction as long as we notify you before doing so; in other cases, we will need your permission before we can revoke the restriction.

5. Right To Request Confidential Communications

- You have the right to request that we communicate with you about your medical matters in a more confidential way by requesting that we communicate with you by alternative means or at alternative locations. For example, you may ask that we contact you by fax instead of by mail, or at work instead of at home. To request more confidential communications, please write to Ms. Lenore Meurer, Privacy Officer c/o Independent Living Association, Inc., 110 York Street, Brooklyn, N.Y. 11201. *We will not ask you the reason for your request, and we will try to accommodate all reasonable requests.* Please specify in your request how or where you wish to be contacted, and how payment for your health care will be handled if we communicate with you through this alternative method or location.