Notification of Rights and Responsibilities, Confidentiality and Grievance Process:

1. You have the right to be treated with dignity, respect and integrity at all times.
2. You have the right to make your own choices about things that matter to you including where you live, who you live with, where you work, and how and where you spend your leisure time.
3. You have the right to say “NO”, decline assistance or can withdraw from SAIL services/programs at any time.
4. You have the right to have your information kept confidential based on HIPAA Regulations and rules of confidentiality as stated in the following SAIL Notice of Privacy Practices:

   Our Privacy and Confidentiality Commitment: Staff at the Southern Adirondack Independent Living (SAIL) Center are committed to protecting your privacy. We understand that information about you is personal, and we will only share information with those who need to know and are allowed to see the information. This notice tells you how SAIL uses and discloses information about you. It describes your rights and the responsibilities of SAIL. When SAIL staff collect medical information from you, it is stored in a file and/or on computer. The record is the property of SAIL, but the information in the record belongs to you. SAIL maintains the record, and protects the privacy of your health information.

   All people who work for SAIL will follow this notice. This includes all employees and persons under contract to SAIL (contractors) who are authorized to establish, maintain, and update your record or provide services to you, as well as volunteers who assist you.

   All information entered into your record that relates to your health or care and treatment is protected. This includes your name, address, birth date, social security number, health insurance plan number and information, clinical diagnoses, medication information, information about your service plan and other information (including photographs or images). This information is referred to as “health information”.

   Throughout this notice, the term “you” means you and/or your personal representative. Depending upon your circumstances and in accordance with state law, your personal representative may be your guardian, health care proxy, power-of-attorney, or your involved parent, spouse or adult child.

   You (or your personal representative) have the following rights concerning your health information:

   - You have a right to see or inspect your medical information and obtain a copy of the information created by SAIL. Some exceptions apply to this right, such as records concerning incident reports and investigations, and information compiled for use in court or administration.
   - If your request to see your medical information is denied, you have the right to request a review of that denial. Professionals chosen by SAIL who were not involved in the initial request will review the record and decide if you may have access to it.
   - You have the right to ask SAIL to change or amend health information that you believe is inaccurate or incomplete. Your request may be denied in some cases. Reasons for denial may include that the record was not created by SAIL, or if after reviewing the request, we believe that the record is accurate and complete.
   - You have the right to request a list of the disclosure(s) that SAIL has made from your record. The list, however, will not include certain disclosures, such as those made for
treatment, payment and health care operations, or disclosures made to you or made to others with your permission.

- You have the right to request a restriction on uses or disclosures of your health information related to treatment, payment, health care operations, and disclosures to involved family. SAIL will review such requests on a case-by-case basis.
- You have the right to request that SAIL communicates with you in any way that will keep your information confidential.
- You have the right to receive a paper copy of this notice. You may request another copy at any time.

To request access to your health information, or to request any of the rights listed above, please contact the center at 518-792-3537 and request to speak to the Assistant Executive Director who is the designated Privacy Officer.

SAIL is required to:

- Maintain the privacy of your information in accordance with federal and state laws.
- Give this notice of our legal duties and practices concerning the health information that we have about you.
- Follow the rules in this notice. SAIL will use or share information about you only with your permission except for the reasons explained in this notice.
- Tell you if we make changes to our privacy practices in the future. If significant changes are made, SAIL will give you a new notice and post it at all work locations.
- Appropriately receive and address all complaints regarding the privacy of your health information.
- Limit all disclosures to the “minimum necessary” to accomplish the purpose of the disclosure.
- Safeguard the privacy of health information through appropriate measure, which will include procedural, physical and technical means.

SAIL may use and disclose health information without your permission for the purposes described below. For each of the categories of uses and disclosures, we have offered an example. Not every disclosure is described, but all disclosures will fall within the listed categories.

- **Treatment:** SAIL will use your health information to provide you with treatment and services. We may disclose health information to other SAIL personnel, volunteers, or interns who are involved in working with you. We may disclose health information to administrative staff who provide oversight of your record. For example: involved staff may discuss your health information to develop and carry out your Independent Living Plan or plan to access services. Other SAIL staff may share your health information to coordinate services that you need including access to benefit and entitlement programs (Social Security, Food Stamps, HEAP, etc.), medical care and tests, transportation, etc. We may also need to disclose your health care information to your Service Coordinator and other providers outside of SAIL who are identified in your Independent Living Plan, Individualized Service Plan, program plan or to obtain new services for you. For example: an advocate may need to disclose your medical diagnosis of traumatic brain injury to access the TBI Regional Resource Development Center (RRDC) operated by SAIL. Additionally, we may use and disclose medical information to contact you or your caregiver as a reminder that you have an appointment for treatment or services.
• **Payment**: SAIL will use your health information so that we can bill and collect payment from you, a third party, an insurance company, Medicare, Medicaid, or other government agencies. For example: we may need to provide the NYS Department of Health with information about the services you received through one of our programs so that they can pay us for the services. In addition, we may disclose your health information to receive prior approval for services that you may need. We may also disclose your health information to the Social Security Administration, the NYS Department of Health, the NYS Office of People with Development Disabilities, the NYS Office of Children and Family Services, or the NY State Education Department to determine your eligibility for coverage or your ability to pay services.

• **Health Care Operations**: SAIL will use health information for administrative operations. These uses and disclosures are necessary to operate the center programs and to make sure that all people receiving services receive appropriate, quality services. For example: we may use health information for quality improvement to review our services and to evaluate the performance of our staff in providing services to you. We will share your health information with other SAIL staff for the purposes of obtaining legal services, conducting fiscal audits, for fraud and abuse detection, and compliance with program standards and operations. We will also share your health information to resolve complaints concerning your services. Additionally, we may disclose your health information to business partners who need access to the information to perform administrative or professional services on our behalf.

Your health information will be used without your permission only for the following reasons:

• When we are required to do so by federal or state law.

• For public health reasons including prevention and control of disease, injury or disability, reporting births and deaths, reporting child abuse or neglect, reporting reactions to medication or problems with products, and to notify people who may have been exposed to a disease or are at risk of spreading the disease.

• To report domestic violence and adult abuse or neglect to government authorities if you agree or if necessary to prevent serious harm.

• For health oversight activities including audits, investigation, surveys and inspections, and licensures. These activities are necessary for the government to monitor the health care system, government programs and services, and compliance with civil rights laws. Health oversight activities do not include investigations that are not related to the receipt of health care or receipt government benefits in which you are not the subject.

• For judicial and administrative proceedings, including hearings and disputes. If you are included in a court or administrative proceeding, we will disclose health information if the judge or presiding officer orders us to share the information.

• For law enforcement purposes in response to a court order or subpoena, to report a possible crime, to identify a suspect or witness, to identify a missing person, or to provide identifying data in connection with a criminal investigation.

• Upon your death to the coroner or medical examiner for identification purposes or to determine cause of death, and to funeral directors to allow them to carry out their duties.

• To organ procurement organizations to accomplish cadaver, eye, tissue, or organ donations in compliance with state law.

• For research purposes when you have agreed to participate in the research, in compliance with all regulations.
• To prevent or lessen a serious and imminent threat to your health and safety or the health and safety of another person.
• To authorized federal officials for intelligence and other national security activities authorized by law or to provide protective services to the President and other officials.
• To correctional institutions or law enforcement officials if you are an inmate and the information is necessary to provide you with health care, if the information is necessary to protect your health and safety and that of others, or for the safety of the corrections institution.
• To government agencies that administer public benefits if necessary to coordinate covered functions of the programs.
• To assist you with accessing Worker’s Compensation or similar programs as a result of a work-related injury or illness.
• To clergy of your religious affiliation as noted in your record.

In the event that SAIL is sold or merged with another organization, your health information will become property of the new owner.

Unless you object, SAIL may disclose health information to the following persons or for the following reasons:

• To family members and/or personal representative who are involved in your care if the information is relevant to their involvement and to notify them of your condition and location.
• As part of normal activities. For example: membership lists, achievement announcements, caseload lists, etc.

For all other disclosures, types and uses not described in this Notice, SAIL will use or disclose health information only with a written authorization signed by you that states who may receive the information, what information is to be shared, the purpose of the use or disclosure, and an expiration for the authorization. Written authorizations are always required for use and disclosure for marketing purposes. Please note that if you cannot give permission due to an emergency, SAIL may release health information in your best interest. We must tell you as soon as possible after releasing the information.

SAIL will not use your photograph or personal information for marketing or fundraising activities without your written permission.

You may revoke your authorization at any time. If you revoke your authorization in writing we will no longer use or disclose your health information for the reason stated in your authorization. We cannot however take back disclosures that we made before you revoked you authorization, we must retain health information that indicates the service(s) that we have provided you.

We do reserve the right to change this notice. We reserve the right to make changes to terms described in this notice, and to make the new notice terms effective to all health information that SAIL maintains. We will post the new notice with the effective date in all of our office locations. In addition, we will offer you a copy of the revised notice at your next scheduled meeting.

Complaints about this Notice of Privacy Practices and how SAIL addresses your health information should be directed to the Assistant Executive Director (Privacy Officer), Anna Livingston, at 518-792-3537, or to the Executive Director, Karen Thayer.

If you are not satisfied with the manner in which SAIL has addressed a complaint, you may submit a formal complaint to:

Department of Health and Human Services
Office of Civil Rights
Hubert H. Humphrey Building
5. You have the right to have your information shared with another person, agency, or organization if you wish ONLY when your written permission has been provided to SAIL (Consent to Release Information) and/or based on the informed consent as stated in the SAIL Notice of Privacy Practices summarized above.

6. You have the right to request copies of everything you receive (Medicaid, SSI, etc. and everything that is written about you (program plans, evaluations, etc.).

7. You have the right to receive accurate and easy to understand information including information in another language or format if needed (electronic format, American Sign Language (ASL), Spanish, large print, Braille, etc.). SAIL is committed to providing equal access to all services and activities provided through the center. Examples of equal access include physical accessibility, the provision of assistive devices, accessible formats, interpreter services, and referral for attendant services, as well as scheduling accommodations. Additional requests for equal access and reasonable accommodations will be reviewed as requested.

8. You have the right to make suggestions and express concerns, complaints or grievances without fear of reprisal, and to initiate a consumer grievance procedure if you feel any action, occurrence or attitude is unfair or inequitable in the delivery of services. Please refer to the following Consumer Grievance Procedure for specific information:

   **Step 1:** As a consumer, you are expected to consult first with the staff member regarding any action, occurrence or attitude, either expressed or implied, which is perceived as unfair or inequitable in regard to delivery of services. If a satisfactory agreement or resolution cannot be made through this consultation, you may appeal in writing to the staff member’s immediate Supervisor.

   **Step 2:** The Supervisor must arrange a meeting with you and the staff member within 10 business days after the grievance is received. If no resolution can be reached at this level, you may appeal in writing to the SAIL Executive Director:

   Karen Thayer  
   71 Glenwood Avenue  
   Queensbury, NY 12804  
   email: sail@sailhelps.org  
   Fax/518-792-0979  
   TTY/518-792-0505

   **Step 3:** If you submit a written grievance to the Executive Director and no resolution can be made within 15 business days after the grievance is received, the Executive Director will instruct the Board President to activate a three member Grievance Committee. This Committee is composed of members of the Board of Directors. The Grievance Committee will hear and review all evidence presented by you and the staff member, and after careful consideration, will make an action recommendation to the President of the Board of Directors within 30 days of the meeting.
The President of the Board of Directors will notify you in writing of the findings of the committee and any actions taken within 10 business days following the meeting.

Step 4: If the action taken by the Grievance Committee and the President of the Board of Directors is not satisfactory to you, a final appeal may be made in writing to the President of the Board of Directors for a hearing before the full Board of Directors or a designated subcommittee thereof. This request must be made in writing and submitted to the Executive Director no more than 10 business days from the date that you receive the above notification from the President of the Board of Directors. The President of the Board of Directors will convene a meeting of the Board of Directors within 15 days of receipt of the notification, and the Board of Directors will hear and review all evidence presented by you and the staff member. You will be notified in writing of the findings of the Board of Directors within 10 business days following the meeting.

Step 5: If the action taken by the Board of Directors is still not satisfactory to you, you may contact ACCES-VR and/or the Client Assistance Program for conflict resolution assistance. If you need assistance and contacting these entities, the Executive Director or designee will assist you in making a referral. ACCES-VR and CAP may be contacted respectively at:

ACCES-VR IL Unit Manager OR NYS CAP Coordinator
NYSED – EBA 5th Floor Client Assistance Program (CAP)
89 Washington Avenue Disability Rights New York
Albany, NY 12234 Disability Advocates, Inc.
518-474-2925 or 1-800-222-5627 (Voice/TTY) 5 Clinton Square, 3rd Floor
5 Clinton Square, 3rd Floor
Albany, NY 12207
1-800-993-8982 (Voice/TTY)
mail@DRNY.org

9. You have the right to control and direct what happens in your life.

10. You have the right to influence laws in your city, state and country.