

Topic: Access of individuals to Protected Health Information	Department: Entire Agency
Original effective date: 4/1/03	Last revision date: 1/12/26
Owner: VP for Quality and Compliance	Frequency of reviews: Annual
Internal/Regulatory Reference(s) (all that apply): 164.524; NYS MHL 33.16; NYS PHL §18	
Related documents/Links: Request for access to PHI Form; Denial of Access to Patient Information and Appeal Form (where PHL prevails): https://health.ny.gov/forms/doh-1989.pdf	

Policy: It is the policy of The Arc of Monroe (“The Arc”) to ensure that people have opportunities for privacy and that business, administrative and support functions promote personal and organizational outcomes.

Additional Information: Any person we support or their legal representative (“person” or “people we support”) has a right to request access to Protected Health Information (PHI) that we maintain about them as part of the designated record set (please cross reference that policy). In some cases, we are required to grant them access, however in other cases we can deny them access.

“Protected health information or PHI” is defined as information about people we support that relates to their past, present or future mental or physical health and also identifies them in some way. In addition to more obvious things such as treatment plans, service documentation, clinical assessment, etc., the following are also considered PHI:

- Initials of someone we support. If you share initials, you are sharing PHI. Reducing a name to initials does not protect it under HIPAA law.
- Pictures of someone we support. This includes any photograph that will identify the person in some way. This may be the case even if their face isn’t visible, but something distinctive about them is. It could also apply to pictures of the back of their head, side shots, other parts of their bodies that are distinctive, etc.
- Anything that describes someone in a way that makes it clear who you are talking about (such as a full physical description; or a combination of characteristics that are so unique as to effectively name the person). EXAMPLE: A short middle-aged woman with blazing red hair and right-side hemiparesis who goes to Henrietta Day Services.

This definition applies whether the information is written, spoken, signed, or in an electronic format – regardless of the language (e.g., English or any other language). You should presume that any information about people we support that you work with in your job is PHI and should be treated as such.

For the purposes of this procedure, “staff” includes employees, contractors, consultants, interns, students and volunteers. The appropriate Senior Director and the VP for Quality and Compliance have primary responsibility for responding to requests for access.

Both the federal government (under HIPAA) and NYS have laws that relate to access to PHI. In some cases, HIPAA will prevail, in other cases, NYS public health law (PHL) will prevail, and in still others, NYS Mental Hygiene Law will prevail. This is determined based on which provides the people we support/their legal representatives with the greatest control over their information.

Based on pre-emption analysis, access to the following PHI is permitted:

- Psychotherapy notes (as defined in HIPAA law 45 CFR 164.501) (PHL prevails). Although under HIPAA law, psychotherapy notes would not be subject to access because they are not included in a designated record set , under NYS PHL §18, people we support/their legal representative have the right to request “patient information maintained by a healthcare provider in New York.” Under pre-emption analysis, this has been interpreted to include psychotherapy notes as defined in HIPAA law. Restrictions to access this would be limited to situations where it’s believed that the release of such information would, “reasonably be expected to cause substantial harm to the patient or others.” Please cross-reference the policy, “Psychotherapy Notes” for further information.
- Personal notes and observations other than psychotherapy notes (HIPAA prevails)
- Information maintained by a practitioner concerning or relating to the prior examination or treatment of a person we support from another practitioner (HIPAA prevails)
- Diagnostic services performed by a practitioner at the request of another practitioner (HIPAA prevails)
- Data disclosed to a practitioner in confidence by other persons on the basis of an express condition that such data would never be disclosed (HIPAA prevails)
- Where access is denied because, in a clinician’s clinical judgment, doing so is reasonably likely to endanger the life or safety of someone, we may grant access to a prepared summary of the information (PHL prevails)

Based on pre-emption analysis, access to the following PHI is restricted/denied:

- PHI that is obtained from someone other than a health care provider under a promise of confidentiality and the access requested would be reasonably likely to reveal the source of the information (HIPAA prevails)
- PHI that references another person and in response, a licensed health care professional in their professional judgment has determined that the access requested is reasonably likely to endanger the life or safety of the subject or another person. (HIPAA prevails specific to information about others and PHL prevails specific to information about the people we support)
- A parental request of information concerning a child over 12 years old if the child objects to the disclosure. Such objection should be formally documented in the person’s designated record set/health record. Parents have no right of access if the minor can lawfully obtain health care service without the consent of a parent. (PHL prevails)
- In regard to a parental request for access, we may deny access to all or part of the information and may grant access to a prepared summary of the information if, after consideration of all the attendant facts and circumstances, we determine that the disclosure would have a detrimental effect on the provider’s professional relationship with an infant, or on the care and treatment of the infant, or on the infant’s relationship with his/her/their parents (PHL prevails)
- Parents have no right to access if the covered entity has a reasonable belief that the child has been or may be subjected to domestic violence, abuse or neglect by the parent or disclosure could endanger the child and The Arc, in the exercise of professional judgment, decides that disclosure is not in the best interest of the child. (PHL prevails)
- Information collected in anticipation of a civil, criminal or administrative action or proceeding (such as a lawsuit) (HIPAA prevails)

Unreviewable grounds for denial of access (under HIPAA):

In the following circumstances, The Arc can deny a person access to PHI without providing them an opportunity for review or appeal:

- Information being collected in anticipation of a civil, criminal or administrative action or proceeding (such as a lawsuit).
- If the PHI was obtained from someone other than a health care provider under a promise of confidentiality and the access would be reasonably likely to reveal the source of the information.

Reviewable grounds for denial of access (under HIPAA):

In the following circumstances where HIPAA prevails, The Arc can deny access to PHI as long as the person is given a right to have such denials reviewed:

- A licensed health care professional has determined that, in their professional judgment, the access requested is reasonably likely to endanger the life or physical safety of the person or someone else.
- The PHI makes reference to another person (other than a health care provider) and a licensed health care professional has determined that, in their professional judgment, the access requested is reasonably likely to cause substantial harm to the person or someone else.

Procedure	
Task:	Responsible party:
General Guidelines	
1. People we support, their legal representatives or guardians have the right to request access to PHI about them that is contained within the designated record set (please cross reference the "Designated Record Set" Policy). They must make such a request in writing using the attached form.	People we support
2. If staff receive such a request, they must forward it to their manager immediately.	Staff
3. If a legal guardian requests to inspect the record of someone we support who is 18 years of age or older, we must notify the person we support of said request (per NYS MHL 33.16(b)(2)).	Manager
4. The manager needs to notify their Senior Director and the VP for Quality and Compliance immediately if they receive such a request.	Manager
5. After reviewing the request, the Senior Director/Vice President may need to reach out to the person to clarify exactly what they are looking for. For example, if they say that they would like a copy of everything we have in our electronic health record for the person, there is likely something specific that they want (as providing copies of everything for some people we support would be an enormous task).	Senior Director/Vice President
6. If The Arc does not maintain the PHI that the person is requesting access to but we know where it is maintained, we are obligated to share that information with the person.	Senior Director
7. The Arc must act on such a request as soon as possible after the request was received. The manager and the VP for Quality and Compliance will work together to respond to the request. Access must be granted within 10 days.	Senior Director, VP for Quality and Compliance

8. The Arc must maintain copies of all documentation related to the request for access, approval or denial, request for review, and review determination for a period of 6 years from the date when the matter is resolved.	VP for Quality and Compliance
If we are granting the request in whole or in part:	
1. The Senior Director will inform the person that the request has been granted in whole or in part. If granted in part only, the senior director will share what information they will be able to have access to.	Senior Director
2. With access granted, the person is entitled to review and/or receive copies of the PHI they have been granted access to.	Senior Director
3. The Arc must provide access to the PHI in the form and format requested by the person, if we are able to do so. For example, if they request to receive the information in electronic format and we can do so, we must.	Senior Director
4. The Arc may provide a summary of the PHI requested, in place of providing access, if the person agrees to it.	Senior Director
5. The Arc will arrange for a convenient time for the person to access the PHI per their request: to either review or receive copies of it.	Senior Director
6. We may, as a provider, request the opportunity to review the information about the person we support with the person making the request; however, this is not required in order to grant the requestor access.	Senior Director
7. If the person requests that The Arc share a copy of the PHI with another person they identify, they have to make that request in writing including to whom and where to send the information. Once we have that, we are obligated to send the information per that request. Please see the attached form.	Senior Director
8. The Arc reserves the right to charge a reasonable cost-based fee of up to \$0.75 per page. However, the release of or access to records cannot be denied solely because of an inability to pay.	VP for Quality and Compliance
If we are denying the request in whole or in part – where HIPAA prevails:	
1. If we are denying any part of the request, The Arc must provide a timely, written denial to the person. It must be written in plain language and include: *The reason(s) we are denying the request *A statement about the person's rights to request a review of the denial and how to exercise those rights *A statement about how the person may complain to The Arc's administration or the federal government. This must include the name and contact information of the Arc person: <Name>, VP for Quality and Compliance; 585-672-2234.	Senior Director
2. If the person has requested a review of a denial, they have a right to the following levels of review.	Person
First level of review:	
1. The first level of review would be with the Director of Nursing, who has been designated as the licensed health care professional to conduct such reviews.	Director of Nursing
2. The Senior Director must promptly refer a request for review to the Director of Nursing.	Senior Director

3. The Director of Nursing must determine within 30 days whether or not to grant or deny the access requested based on the standards list in the HIPAA law.	Director of Nursing
4. If the decision is to grant the request, then the access requested may be permitted, consistent with the section above on granting access.	Senior Director
5. If the decision is to deny the request, the person has the right to proceed to the second level of review.	Person
Second level of review:	
1. If the person disagrees with the decision of the Director of Nursing, they can request a review by the OPWDD Clinical Record Appeal Review Committee.	Person
This is done by writing a letter to the Office of Counsel at OPWDD. The person will not have to pay anything for this second review.	
2. If the committee's decision is to grant the request, then the access requested may be permitted, consistent with the section above on granting access.	Senior Director
3. If the committee's decision is to deny the request, the person has the right to proceed to the third level of review.	Person
Third level of review:	
1. If the person disagrees with the decision of the OPWDD Clinical Record Appeal Review Committee, within 30 days of receiving notification of the committee's decision, they can seek judicial review of The Arc's original decision to deny the access.	Person
2. If the person chooses this route, we will consult with our legal counsel on how we should proceed.	VP for Quality and Compliance
3. If either The Arc decides to agree to the request at this point or the judicial review's decision is to grant the request, then the access requested may be permitted, consistent with the section above on granting access.	Senior Director
4. If the issue proceeds to judicial review and its decision is to deny the request, then the request for access will be denied to the person by The Arc.	VP for Quality and Compliance
If we are denying the request in whole or in part – where PHL prevails:	
1. If we are denying any part of the request, The Arc must provide a timely, written denial to the person. It must be written in plain language and include: *The reason(s) we are denying the request *A statement about the person's rights to request a review of the denial and how to exercise those rights *A statement about how the person may complain to The Arc's administration or the federal government. This must include the name and contact information of the Arc person: <Name>, VP for Quality and Compliance; 585-672-2234.	Senior Director
2. If the person has requested a review of a denial, they have a right to the following levels of review.	Person

First level of review:	
1. The first level of review would be with the NYS Department of Health (DOH) Medical Record Access Review Committee. Please see the link in the header to the appropriate form. The person or their legal representative should contact the NYS DOH for more information.	Person/Legal representative
Second level of review:	
1. If the person disagrees with the decision of the NYS DOH Medical Record Access Review Committee, they can request a judicial review within 30 days of receiving the committee's decision.	Person
2. If the person chooses this route, we will consult with our legal counsel on how we should proceed.	VP for Quality and Compliance
3. If either The Arc decides to agree to the request at this point or the judicial review's decision is to grant the request, then the access requested may be permitted, consistent with the section above on granting access.	Senior Director
4. If the judicial review decision is to deny the request, then the request for access will be denied to the person by The Arc.	VP for Quality and Compliance
Manager responsibilities:	
1. Managers have a responsibility to notify their Senior Director immediately if they receive a request for access to records.	Managers
Senior Director responsibilities:	
1. Senior Directors have responsibilities for ensuring that the information we are granting access to is compiled and ready for inspection or copying within required timelines.	Senior Director
2. The Senior Director will work with the VP for Quality and Compliance around decisions for granting and/or denying access to requested information.	Senior Director
VP for Quality and Compliance:	
1. Acts as the agency's Privacy Officer	VP for Quality and Compliance
2. Responsible for administering the agency's HIPAA privacy policies and procedures.	VP for Quality and Compliance
3. Acts as a resource for staff in regards to proper implementation of the HIPAA privacy rule.	VP for Quality and Compliance

Document revision record:

Revision Date	Release Date	Reason for change	Approver
9/12/08	9/12/08	Reasons for change not documented	P Dancer
8/6/10	8/6/10	Reasons for change not documented	P Dancer
10/21/11	10/21/11	Reasons for change no documented	P Dancer
8/5/15	8/5/15	Reasons for change no documented	P Dancer
8/4/17	8/4/17	Reasons for change no documented	P Dancer
11/20/18	11/20/18	Reasons for change no documented	P Dancer

1/27/21	1/27/21	Transitioned to new procedural format and fleshed out responsibilities	P Dancer
1/24/23	1/24/23	Formally incorporated NYS PHL section 18 and NYS MHL section 33.16 into the text; Clarified linked documents and added links	ICC
1/25/24	1/25/24	Removed name of Privacy Officer and replaced with a place holder	ICC
12/16/24	1/23/25	Added clarifying language	ICC
1/12/26	1/12/26	Clarified the section on access to psychotherapy notes with pre-emption information; added additional clarifying information	ICC

REQUEST FOR ACCESS TO PHI FORM

The Arc of Monroe

Name of person: _____
Address: _____
City, State, Zip: _____
Date of Birth: _____

I am requesting to inspect and/or receive a copy of my Protected Health Information in The Arc of Monroe's Designated Record Set pursuant to HIPAA Right of Access regulations. I am requesting records from the following program sites:

All program sites Specific program sites(s): _____

Please produce records for the following dates: from ____/____/____ to ____/____/____ or "Present" (which equals date of signature)

Specific PHI to Release: (Check box of items to be released)

<input type="checkbox"/> ISP/Life Plan	<input type="checkbox"/> Behavior support data
<input type="checkbox"/> Habilitation or Staff Action Plan	<input type="checkbox"/> Med Administration Records
<input type="checkbox"/> Clinic Treatment Plan	<input type="checkbox"/> Support guidelines or protocols (i.e., ambulation, eating)
<input type="checkbox"/> Clinical assessment: (Specify discipline(s): _____)	<input type="checkbox"/> Discharge summary
<input type="checkbox"/> Appointment summaries	<input type="checkbox"/> Other: _____
<input type="checkbox"/> Clinical or nursing notes	_____
<input type="checkbox"/> Service documentation or notes (incl. monthly summaries)	_____
<input type="checkbox"/> IPOP	_____
<input type="checkbox"/> Behavior support plan	_____

I am requesting that this PHI be sent in the selected form or format:

Recipient: Myself My Legal Representative Other

Name: _____

Address: _____

Phone: _____

Email: _____

Format: From Electronic Health Record (pdf)

Certified US Mail (paper format)

Encrypted flash drive

Secure email (encrypted)

Unsecured email (The Arc is not responsible for improper access)

Other: _____

PLEASE NOTE: I understand that if I ask The Arc of Monroe to disclose PHI to another individual or entity, that information may no longer be protected by New York State and Federal privacy laws, including HIPAA. I understand that The Arc of Monroe will make reasonable attempts to produce the documents in the format requested; however, if the records are not readily reproducible in that format, The Arc will contact you to discuss alternative delivery options. In certain limited circumstances, The Arc of Monroe may deny a request. If a request is denied, I understand I will be given a written explanation, and a description of steps I may take in response to the denial.

SIGNATURE

Date/Time: _____ Signature: _____

Relationship to the person listed above:

Self

Legal representative of this person (must use the first present on the following list):

- Court-appointed guardian
- Actively involved spouse
- Actively involved parent
- Actively involved adult child
- Actively involved adult sibling
- Actively involved family member