



# HealthAssistance

## PARTNERSHIP

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Issue Brief

## Health Insurance Portability and Accountability Act (HIPAA) Privacy Regulation: Questions and Answers For Consumer Health Assistance Programs

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The HIPAA privacy regulation went into effect April 14, 2003. The regulation explains when an individual has a right to obtain medical records and other health information and when health plans, health care providers, and health care clearinghouses, called “covered entities,” can share protected health information with other people or entities.

Consumer health assistance programs use protected health information in their daily work. The following Q & A guides consumer health assistance programs through their rights and responsibilities under the HIPAA privacy regulation. Programs may be affected by the regulation in several ways. Whether they are housed in government or in independent nonprofit agencies, virtually all consumer health assistance programs obtain health information on behalf of an individual to assist in resolving health care disputes. Generally, to obtain medical records, they will need to use authorization forms that comply with HIPAA. Some consumer health assistance programs have special rights of access to medical records because they are in “health oversight agencies.” Others have rights to exchange information with a particular health agency or health plan because they are a “business associate” of that agency or plan.

1. Do individuals have a right to their health records? Can a consumer health assistance program obtain records on behalf of an individual?

Individuals have a *right of access* to inspect and obtain a copy of health records about themselves. Individuals can authorize another person or a consumer health assistance program to obtain records on their behalf. A health plan, health clearinghouse, or health care provider is *permitted* to disclose records to anyone or any organization that has a valid, HIPAA-compliant authorization from the individual to obtain medical records concerning the individual. The plan, clearinghouse, or provider is *required* to disclose records to an individual about himself or herself or to a personal representative who is authorized to make health care decisions for that individual.

Generally, consumer health assistance programs will not be considered personal representatives if they are not making decisions about a consumer's health care. Other state or federal laws may give some consumer health assistance programs rights of access to records on authorization from an individual or rights to review records in conjunction with mandated health oversight activities. However, if no such laws give a program a right of access and a health plan or provider is unwilling to disclose records to a consumer health assistance program, an individual can request his or her own records and then share the records with the program.

There are three distinct instances in which individuals do not have a right of access, and most programs may, therefore, be unable to get access to individuals' records. Exceptions to individuals' right of access to their health care records are for psychotherapy notes (see Q&A 3); information "compiled in reasonable anticipation of, or for use in, a civil, criminal, or administrative action or proceeding";<sup>1</sup> and information for which access is controlled under the Clinical Laboratory Improvements Amendments of 1988.<sup>2</sup>

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<sup>1</sup> 45 CFR § 164.524(a)(1).

<sup>2</sup> See *Rights to Access Medical Records Under the HIPAA Privacy Regulation* (Washington, DC: Health Assistance Partnership, April 2003) and 45 CFR §§ 164.502 and 164.524 for details on when access can be denied and what recourse consumers have if access is denied.

## 2. How should consumer health assistance programs modify their authorization forms in order to request medical records protected by the HIPAA Privacy Regulation?

Authorization forms to request medical records must be separate from any more general authorization forms (such as an authorization to represent an individual) used by your program. The authorization form for medical records must be in plain language and contain all of the following:<sup>3</sup>

- a) Space to specify the information you are authorized to obtain on behalf of the individual. For example, the form might authorize you to receive medical records related to a particular diagnosis or treatment period or to receive the entire medical record of a particular provider for a client.
- b) If your state laws have more stringent requirements (such as special permission to release HIV or substance abuse treatment records), space to check off any specific permission to release this information.<sup>4</sup>
- c) Your name and your organization's name as the entity that will receive the information.
- d) Space to enter the name(s) of the individuals, agencies, or organizations that the individual authorizes to release records to you.
- e) The purpose for which you are requesting the records. The purpose can be a very general statement that the records will be used "at the request of the individual" because under the regulation, an individual initiating an authorization does not need to explain his or her purpose.
- f) An expiration date (e.g., "this authorization is good from month/date/year to month/date/year") or an expiration event (e.g., "this authorization is good from month/date/year until completion of the external review of my managed care appeal").
- g) Space for the individual's signature and date of signature.

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<sup>3</sup> 45 CFR §164.508(b) and (c).

<sup>4</sup> HIPAA preempts state laws unless the state laws are "more stringent." With respect to the right of an individual to obtain his or her own health records, state laws that permit *greater* rights of access are considered more stringent and are not preempted. With respect to the need to express permission from the individual for use or disclosure of health information, state laws that increase privacy protections are more stringent and are not preempted (45 CFR §§160.202 and 160.203).

<sup>5</sup> 45 CFR § 169.508(b)(3) and preamble in *Federal Register* vol. 65, no. 250, December 28, 2000, p. 82516.

You must use a separate authorization form to request psychotherapy notes. An authorization for psychotherapy notes cannot be combined with an authorization for other medical records.<sup>5</sup>

Make sure the form includes statements notifying the signer of the following:

- a) He or she has the right to revoke the authorization in writing. The form should explain how the individual would do this—e.g., to whom he or she would give a written revocation.<sup>6</sup> (However, an individual cannot revoke authorization for information that has already been lawfully released.)
- b) If applicable, the information disclosed pursuant to the authorization will no longer be protected under HIPAA and may be subject to further disclosure. This statement should be written according to the laws that apply to your program. For example, if your program is a covered entity (part of a health plan, health care clearinghouse, or health provider), the statement may not be applicable because you are bound by HIPAA requirements about redisclosure. If information that you receive is protected under other state or federal confidentiality laws, explain those protections. Even if there is not a law requiring you to do so, you can state that though the information disclosed is no longer protected by HIPAA or other laws, you agree to keep the information confidential and will only exchange information with a health plan, appeals board, or other agency for the purpose of assisting the individual.

If you are a covered entity under the HIPAA regulation (for example, an ombudsman program within a Medicaid agency may be a covered entity),<sup>7</sup> in addition to the above requirements:

- a) You *must* give a copy of the signed authorization to the individual; and
- b) You must include a statement that the entity (the health plan, Medicaid agency, or provider of which you are a part) may not condition eligibility for benefits, enrollment in a health plan, or treatment on whether the individual signs the authorization.

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<sup>6</sup> You may want to advise the consumer to send copies of the revocation both to your program and to any individual, agency, or organization that was authorized to release records to your program.

<sup>7</sup> See 45 CFR § 164.504 (a)-(c) and “Covered Entity Decision Tools” at <http://www.cms.gov/hipaa/hipaa2/support/tools/decisionsupport/default.asp>

Even if you are not required to do so under HIPAA, it is good practice for all programs to give a copy of the signed authorization to the individual. The consumer should retain a record of what information you have his or her permission to obtain and how the information may be used.

For samples of authorization forms developed by Health Law Advocates, Inc., go to [http://www.healthassistancepartnership.org/site/DocServer/HIPAA-Complaint\\_PHI\\_Release\\_Form\\_11APR03.pdf?docID=502](http://www.healthassistancepartnership.org/site/DocServer/HIPAA-Complaint_PHI_Release_Form_11APR03.pdf?docID=502); and for forms developed by the HIPAA Collaborative of Wisconsin, go to <http://www.hipaacow.org/hipaacow/documentation.htm>.

### 3. What requirements apply to requests for psychotherapy notes?

Psychotherapy notes are narrowly defined in the regulation as “notes recorded (in any medium) by a health care provider who is a mental health professional documenting or analyzing the contents of conversation during a private counseling session or a group, joint, or family counseling session and that are separated from the rest of the individual’s medical record.”<sup>8</sup> Authorizations for use or disclosure of psychotherapy notes must be separated from authorizations to get other records. The regulation states: “An authorization for a use or disclosure of psychotherapy notes may only be combined with another authorization for a use or disclosure of psychotherapy notes.”<sup>9</sup>

Individuals do not have a *right of access* to inspect and obtain a copy of psychotherapy notes about themselves that are separated from the rest of the medical record, so even with an authorization, in most instances, the health plan or provider can deny a request for psychotherapy notes from a consumer health assistance program or an individual. Disclosure of psychotherapy notes to an agency *might be required by a law* that governs health oversight of the psychotherapist or when there is a threat to health or safety or if a death is under investigation. A mental health ombudsman might be authorized by law to receive notes in conjunction with such oversight or investigation.<sup>10</sup>

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<sup>8</sup> 45 CFR § 164.501.

<sup>9</sup> 45 CFR § 164.508 (b)(3).

<sup>10</sup> See 45 CFR §§ 164.524 and 164.508.

4. Will covered entities honor signed authorization forms sent by fax or e-mail?

Since nothing in the regulation prohibits the use of a faxed or e-mailed authorization that includes a signature, such as a faxed or digital signature, a covered entity should honor such an authorization.

5. Must the health plan or provider give an individual his or her full medical record, including medical records originally developed by previous providers?

In its “Frequently Asked Questions” Web pages regarding “Privacy of Health Information,” the Office of Civil Rights (OCR), U.S. Department of Health and Human Services (HHS), clarifies that an individual can ask for and receive his or her *entire* medical record and need not provide the reason for the request<sup>11</sup> and that a treating provider can release the portions of the medical record developed by former providers as well as the portions developed by the current provider.<sup>12</sup> A consumer health assistance program should, therefore, be able to obtain the full medical record if the program is properly authorized to obtain records for an individual.

6. What can a provider charge for copying medical records? To whom can you complain if the charges seem excessive?

Under the HIPAA privacy regulation, the provider or other covered entity can charge an *individual* “reasonable, cost-based fees.” The fee can include only the costs of copying (including supplies and labor) and postage but *not* the cost of searching for and retrieving records. If the patient requests a summary or explanation of the records, the entity can charge a fee for preparing the summary or explanation.<sup>13</sup> Thus, a program may want to assist the individual in requesting his or her own records in order to avoid unregulated fees. If the individual is charged excessive fees, see Q&A 12 about how to complain.

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<sup>11</sup> See “Under what conditions may a health care provider use, disclose, or request an entire medical record?” on <http://answers.hhs.gov> and 45 CFR § 164.508(c).

<sup>12</sup> “May a health care provider disclose parts of a medical record that were created by another provider?” on <http://answers.hhs.gov>.

<sup>13</sup> See 45 CFR §164.524 and “If patients request copies of their medical records, are they required to pay for the copies?” on <http://answers.hhs.gov>.

Additional restrictions on charges may apply under other state and federal laws. A state law may prohibit charging for records used to establish eligibility for benefits for low-income people. Under federal Medicaid rules, participating providers must accept Medicaid rates as “payment in full” and can only charge their patients nominal copayments for services as specified by the state’s Medicaid plan. Similarly, Medicaid managed care plans agree to accept the state’s rates as payment in full for administering and providing benefits to enrollees. Since Medicaid

managed care regulations explain that enrollees have a right to obtain their medical records, you may be able to argue that the plan is responsible for furnishing those records to enrollees without charge, and you might complain to the state Medicaid agency or request a fair hearing to dispute charges to the Medicaid beneficiary.

7. My program normally does its work by phone. How can I get a health plan or provider to talk to me if I don't have a written authorization from the individual?

In some circumstances, individuals can give oral consent. Some relevant information is not considered protected health information. Some programs do not need written authorization to get protected health information.

- You may be able to set up a three-way telephone conversation with the individual and the plan or provider and yourself, where the individual can consent for the plan or provider to give you oral information. The individual can also request and be given information about his or her own medical records and can then consult with you about how to use or interpret the information. The regulation states that if an individual is present or otherwise available and agrees to a use or disclosure of protected health information, a covered entity can disclose the protected health information to a personal representative or another person involved in the individual's care or payment for the individual's care without a written authorization.<sup>14</sup>
- You can talk to the health plan about non-personal information. For example, you can ask about utilization criteria generally rather than about a specific individual.
- You may be able to negotiate for an individual based on what the individual has told you about his or her case without asking the provider or plan to disclose further protected information.
- If your program is part of a government health oversight agency, plans and providers may be required to give you information necessary to carry out your oversight role without specific written authorization from the individual. Consult with your agency's privacy officer for more information.

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<sup>14</sup> 45 CFR § 164.510(b)(2).

8. My ombudsman program is authorized by state law to review all health plan notices of denial and/or to investigate injuries and deaths. Will the privacy regulation prevent me from obtaining these denial notices or from conducting investigations without individual authorizations?

If your program is authorized by law to do these reviews or investigations, it is probably considered a “health oversight agency” under the HIPAA regulation. Health oversight agencies do not need individual written authorizations to conduct oversight activities relating to receipt of health care, claims for public benefits related to health, or claims for public benefits or services for which the patient’s health is integral to his or her eligibility.<sup>15</sup>

Health oversight agencies have special access to medical records to conduct oversight activities authorized by law. Health oversight agencies can include both public agencies and persons or entities acting under a grant of authority or contract from a public agency that is authorized by law to oversee the health care system. Health oversight agencies also include agencies (or their contractors) that “oversee government programs in which health information is necessary to determine eligibility or compliance or enforce civil rights laws for which health information is relevant.”<sup>16</sup>

The Administration on Aging has determined (and OCR has concurred) that representatives of the Long-Term Care Ombudsman Program are health oversight agencies because they have oversight responsibilities authorized by law for a component of the health care system (Administration on Aging, Information Memorandum, “Ombudsman Access to Residents’ Records and Other Information,”

<http://www.aoa.gov/im/Info%20Memorandum,%20HIPAA.pdf>).

The same principles could apply, for example, to mental health ombudsmen that are authorized by law to review the quality of care provided to mental health patients.

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<sup>15</sup> 45 CFR § 164.512(d).

<sup>16</sup> 45 CFR § 164.501.

9. I am in a nonprofit that contracts with the Medicaid agency to assist managed care consumers. In the past, I have had access to online Medicaid eligibility and health plan enrollment information for individuals. Does the privacy regulation prohibit such access?

You may be a “business associate” (as defined under HIPAA<sup>17</sup>) of the Medicaid agency because under contract, you assist the Medicaid agency in a function or activity involving the use or disclosure of protected health information. The Medicaid agency may disclose protected health information to you if you have a formal contract or agreement that assures the Medicaid agency that you will appropriately safeguard the information.

The contract between the covered entity and a business associate must<sup>18</sup>

- Specify when the business associate is permitted and required to use and disclose health information;
- Provide that the business associate will use appropriate safeguards to prevent use or disclosure of information that is not provided for by its contract;
- Provide that the business associate will report to the covered entity if it becomes aware of any use or disclosure of information not permitted under its contract;
- Ensure that any agents or subcontractors of the business associate similarly agree to the same restrictions or conditions on use and disclosure of information;
- Provide that the business associate will follow all of the federal regulations to ensure access for an individual to his or her own records, to give individuals the right to amend their health information or records, and to give individuals an accounting of any disclosures of his or her protected health information made by the business associate during the six years prior to the date of an individual’s request for an accounting;<sup>19</sup>
- Provide that the business associate will make its internal practices, books, and records related to use and disclosure of protected health information available to HHS for the purpose of proving compliance; and
- Provide that when the contract terminates, the protected health information will be returned to the covered entity or destroyed or, if this is not feasible, that the standards

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<sup>17</sup> 45 CFR § 160.103

<sup>18</sup> See 45 CFR §164.504(e)(2) and § 164.532 for further details. Some business associates and covered entities that have a non-HIPAA compliant contract or agreement may be given an extension until April 14, 2004 to bring the agreement into compliance.

<sup>19</sup> 45 CFR §164.528 (a) (2)(3).

for privacy of health information under the contract will be extended.

10. My program is located in the Department of Health. What determines whether my program is a “covered entity,” and what difference will it make?

State, county, and local health departments are covered entities if they perform functions defined in the law—that is, if they act as a health plan (which includes Medicaid agencies), a health care clearinghouse, or a health care provider that electronically transmits health information in standard format. Health departments that perform some covered functions and other functions that are not defined in the law can designate which parts of the department perform covered functions. The department as a whole would then be considered a “hybrid entity,” and specific rules govern how the covered and noncovered parts of the department can share information. HHS’s “Covered Entity Decision Tools” at <http://www.cms.gov/hipaa/hipaa2/support/tools/decisionsupport/default.asp> can help you determine whether your department and your program fit the definition of a covered entity.<sup>20</sup>

11. When can a “covered entity” communicate with a family member about an individual’s health care?

Usually, a parent is treated as a minor child’s personal representative and has the right to see medical records and receive health information about the minor child.<sup>21</sup> The following are exceptions to this right: when the minor receives care and the consent of the parent is not required under law; when care is provided under court order; when the parent agrees that the child and health care provider may have a confidential relationship; and when the provider reasonably believes that the minor may be subject to domestic violence, abuse, or neglect and that the parent could endanger the child.

A family member may have the right to see medical records of an adult or emancipated minor if the family member is that individual’s “personal representative” (as defined under other laws) and has authority to make health care decisions for the individual.<sup>22</sup> Under HIPAA, the personal representative has the right to see only records that are *relevant to his or her authority*. For

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<sup>20</sup> Also see “Are State, county or local health departments required to comply with the HIPAA Privacy Rule?” on <http://answers.hhs.gov> and 45 CFR §164.504(a)-(c).

<sup>21</sup> 45 CFR § 164.502 (g).

<sup>22</sup> 45 CFR §165.502 (g).

example, if the representative's authority is limited to decisions regarding life supports, then the representative may only be allowed to see records relevant to his or her decision about whether to authorize life supports.

Finally, family members and friends may obtain some types of health information that do not require a written authorization:<sup>23</sup>

- 1) A health care facility may list an individual's name, location, and general condition (but not specific medical information) in a facility directory unless the individual objects and can disclose this information to people asking about the individual by name. The facility can also disclose the individual's religious affiliation to clergy if the individual *does not object*. If the person is incapacitated or in emergency treatment, the information can be disclosed unless the individual previously expressed an objection or the facility determines that disclosure would not be in the individual's interest.
  
- 2) When a family member, other relative, or close personal friend is involved in an individual's care or payment for that individual's care, a covered entity can notify the relative or friend about the individual's location and general condition. The covered entity can also disclose information relevant to the other's involvement in the care or in payment for the care. These disclosures can be made if the individual is present and *agrees or does not object*. When the individual cannot practically consent because, for example, he or she is in an emergency circumstance or incapacitated, the covered entity can make a professional judgment about whether disclosure is in the interest of the individual and can disclose information relevant to the other person's involvement with the individual's health care. (A covered entity can notify family members, relatives, close personal friends, and relevant

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<sup>23</sup> 45 CFR §164.510.

agencies about a person's location without getting consent if necessary to respond to an emergency circumstance.)

12. How can my program or an individual file complaints about violations of the privacy regulation?

Anyone who believes that a covered entity is not complying with the HIPAA privacy regulation can file a complaint with the Office for Civil Rights, U.S. Department of Health and Human Services, either electronically at [OCRcomplaint@hhs.gov](mailto:OCRcomplaint@hhs.gov) or by fax or mail to the appropriate regional office of OCR (see list of regional offices on pages 13-15). People may complain, for example, if a covered entity does not properly provide individuals or others referenced in the regulation access to health information, if a provider charges excessive amounts for copying records, or if an entity does not properly safeguard health information. Complaints must be filed within 180 days of when the complainant knew or should have known about the violation.<sup>24</sup> (The time limit can be waived for good cause.) The Health Privacy Project, a nonprofit organization, has developed a complaint form to use and, if the consumer agrees, is interested in receiving copies of complaints that you file with OCR. This form is at [http://www.healthprivacy.org/usr\\_doc/PrivComplaintForm.pdf](http://www.healthprivacy.org/usr_doc/PrivComplaintForm.pdf)

13. What happens when a complaint is filed?

After investigating a complaint, if HHS finds that a covered entity is not in compliance with the privacy regulation, HHS will contact the covered entity and first try to resolve the problem informally and if informal resolution is not possible will issue written findings. HIPAA does not provide any further enforcement mechanism. Some state privacy laws give consumers the right to sue providers for violations of privacy rights, a mechanism that is not provided under HIPAA. Advocates in states with such laws should see whether their state laws incorporate either HIPAA privacy standards or more stringent privacy standards so that the state laws and their enforcement mechanisms will not be preempted by HIPAA.

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<sup>24</sup> 45 CFR § 160.306.

The following list of regional offices was obtained from the Office for Civil Rights:

**Regional Offices for Civil Rights**

**Region I - Boston (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont)**

Peter Chan, Acting Regional Manager  
Office for Civil Rights  
U.S. Department of Health and Human Services  
Government Center  
J.F. Kennedy Federal Building - Room 1875  
Boston, MA 02203  
Voice phone(617)565-1340  
FAX (617)565-3809  
TDD (617)565-1343

**Region II - New York (New Jersey, New York, Puerto Rico, Virgin Islands)**

Michael Carter, Regional Manager  
Office for Civil Rights  
U.S. Department of Health and Human Services  
Jacob Javits Federal Building  
26 Federal Plaza - Suite 3312  
New York, NY 10278  
Voice Phone (212)264-3313  
FAX (212)264-3039  
TDD (212)264-2355

**Region III - Philadelphia (Delaware, District of Columbia, Maryland, Pennsylvania, Virginia, West Virginia)**

Paul Cushing, Regional Manager  
Office for Civil Rights  
U.S. Department of Health and Human Services  
150 S. Independence Mall West  
Suite 372, Public Ledger Building  
Philadelphia, PA 19106-9111  
Main Line (215)861-4441  
Hotline (800) 368-1019  
FAX (215)861-4431  
TDD (215)861-4440

**Region IV - Atlanta (Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee)**

Roosevelt Freeman, Regional Manager  
Office for Civil Rights  
U.S. Department of Health and Human Services  
Atlanta Federal Center, Suite 3B70  
61 Forsyth Street, S.W.  
Atlanta, GA 30303-8909  
Voice Phone (404)562-7886  
FAX (404)562-7881  
TDD (404)331-2867

**Region V - Chicago (Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin)**

Lisa Simeone, Regional Manager  
Office for Civil Rights  
U.S. Department of Health and Human Services  
233 N. Michigan Ave., Suite 240  
Chicago, IL 60601  
Voice Phone (312)886-2359  
FAX (312)886-1807  
TDD (312)353-5693

**Region VI - Dallas (Arkansas, Louisiana, New Mexico, Oklahoma, Texas)**

Ralph Rouse, Regional Manager  
Office for Civil Rights  
U.S. Department of Health and Human Services  
1301 Young Street, Suite 1169  
Dallas, TX 75202  
Voice Phone (214)767-4056  
FAX (214)767-0432  
TDD (214)767-8940

**Region VII - Kansas City (Iowa, Kansas, Missouri, Nebraska)**

Fred Laing, Acting Regional Manager  
Office for Civil Rights  
U.S. Department of Health and Human Services  
601 East 12th Street - Room 248  
Kansas City, MO 64106  
Voice Phone (816)426-7277  
FAX (816)426-3686  
TDD (816)426-7065

**Region VIII - Denver (Colorado, Montana, North Dakota, South Dakota, Utah, Wyoming)**

Velveta Howell, Regional Manager

Office for Civil Rights

U.S. Department of Health and Human Services

1961 Stout Street — Room 1185 FOB

Denver, CO 80294-3538

Voice Phone (303)844-2024

FAX (303)844-2025

TDD (303)844-3439

**Region IX - San Francisco (American Samoa, Arizona, California, Guam, Hawaii, Nevada)**

Ira Pollack, Regional Manager

Office for Civil Rights

U.S. Department of Health and Human Services

50 United Nations Plaza - Room 322

San Francisco, CA 94102

Voice Phone (415)437-8310

FAX (415)437-8329

TDD (415)437-8311

**Region X - Seattle (Alaska, Idaho, Oregon, Washington)**

Linda Yuu Connor, Deputy Regional Manager

Office for Civil Rights

U.S. Department of Health and Human Services

2201 Sixth Avenue - Suite 900

Seattle, WA 98121-1831

Voice Phone (206)615-2287

FAX (206)615-2297

TDD (206)615-2296

The **Health Assistance Partnership** provides support to the approximately 1,300 consumer health programs across the country. The Health Assistance Partnership's mission is to help these programs to serve and educate health care consumers and to advocate for consumers' health care rights. These programs provide services to individuals and families whether they are privately insured, publicly insured, or uninsured. A project of Families USA, the Health Assistance Partnership is funded by the Robert Wood Johnson Foundation and has as its partners the Alliance of Community Health Plans, the American Hospital Association, and the American Nurses Association.

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