

DATA SYSTEMS AND CONFIDENTIALITY WORK GROUP

RECOMMENDATIONS ON CONFIDENTIALITY DECEMBER 2001

INTRODUCTION

Information sharing among caseworkers is critical to the provision of coordinated services, and the collection of data is essential for measuring outcomes. At the same time, concerns have been raised about balancing the need to protect a client's confidentiality with a caseworker's need to know and share essential information in order to provide the most comprehensive services.

When dealing with sensitive information, a guarantee of confidentiality is essential to protect privacy and encourage client participation in many programs. However, it is important to ensure that confidentiality concerns are not used to derail coordination of services provided by CalWORKs and Child Welfare Services (CWS), as well as child care, mental health, substance abuse, and housing assistance services. To this end, the Data Systems and Confidentiality Work Group determined that confidentiality protocols *already exist* to safeguard privacy concerns *and* allow respectful transfer of information among caseworkers. The goal for counties, then, becomes one of identifying and implementing methods to protect client confidentiality while sharing necessary information in coordinated programs.

The Work Group offers three recommendations to support counties in developing clear and effective confidentiality protocols.¹

- 1. Establish clear confidentiality protocols and educate staff.**
- 2. Educate clients on their right to confidentiality.**
- 3. Involve and inform community-based organizations.**

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Data Systems and Confidentiality Work Group

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¹ The Work Group also made state-level recommendations, which are contained in the document, *Recommendations for State-Level Activities to Coordinate CalWORKs and Child Welfare Services*.

RECOMMENDATIONS

1. Establish Clear Confidentiality Protocols and Educate Staff.

The Work Group identified a number of benefits from establishing clear confidentiality protocols (see Table 1). However, in some counties, barriers often inhibit respectful and appropriate sharing of information (see Table 2), which restricts coordination of services. *All* of these barriers can be addressed through education, which is the focus of six strategies recommended by the Work Group.

- Identify confidentiality barriers in the agency.
- Establish written policies and protocols.
- Provide ongoing training sessions.
- Build relationships that facilitate communication and build trust.
- Provide desk guides.
- Establish in-house confidentiality experts.

- **Identify confidentiality barriers.**

To determine how confidentiality concerns inhibit coordination of services, county leaders need to interview their staff. Some counties have surveyed staff informally, and it is also possible to use focus groups. Once concerns are identified, protocols and training can be designed to address the issues.

- **Establish written policies and protocols.**

It is possible to establish written policies and protocols that allow respectful transfer of information while safeguarding client privacy. The procedures must include county-specific requirements, as well as reference to applicable law and regulations.

Two publications that provide complete and comprehensive information on all aspects of confidentiality are:

- *Glass Walls: Confidentiality Provisions and Interagency Collaborations*, Youth Law Center, 1993.
- *Confidentiality: A Manual for the Exchange of Information in a California Integrated Children's Services Program*, Cathie Wright Technical Assistance Center, 1999.

Joint confidentiality policy and procedures between CalWORKs and CWS need to be in place to guarantee that staff in both programs understand the information-sharing policies. Involve partner agencies, client advocates, and community-based organizations (CBOs), such as those providing domestic violence, mental health, and substance abuse services, in the development of policy and procedures. These partners provide a unique and valuable perspective on sharing information that will ensure sound policy.

The Office of the County Counsel can play a constructive role not only in developing county-specific policies and protocols, but also in training (see Table 3).

Table 1
Benefits of Establishing Clear Confidentiality Protocols

- Shared decision making and responsibility
- A more complete knowledge base leading to an optimal service plan.
- Fewer gaps in service to families
- Less duplication of services and greater efficiency in service delivery
- Sharing of data system-wide allows for more accurate measurement of outcomes and objectives
- Breaches in confidentiality are less likely to occur

Table 2
Barriers to Information Sharing

- Clear protocols and training on confidentiality have not been established.
- Agency staff do not have a clear understanding of the protocols and practices relating to confidentiality.
- Clients are reluctant to share information when it is unclear to them how the information will be used and by whom.
- The benefits of instituting clear confidentiality protocols have not been a priority.

- **Provide ongoing training sessions.**
A comprehensive confidentiality training package must be provided to educate county staff on applicable laws and regulations, county-specific policies and procedures, release forms, county counsel legal opinions, and desk guides. Due to staff turnover, training must be available and provided to staff on an ongoing basis. Training sessions should be conducted with CalWORKs, CWS, and community partner staff together. New employee orientation should also include training on confidentiality protocols.

- **Build relationships that facilitate communication and build trust.**
People who do not know one another will understandably have a more difficult time sharing confidential information. Thus, it is important for county leadership to offer opportunities, both formal and informal, for CalWORKs, CWS, CBO staff, and client advocates to get to know one another. Joint meetings on a regular basis can be established for this purpose. New employee orientations should include staff from all programs. Creating multi-disciplinary teams with both CWS and CalWORKs staff is another approach.

- **Provide desk guides.**
Even with clear county policies and protocols, confidentiality laws and provisions are complex, extensive, and program specific. A concise Desk Guide for staff and community partners could summarize county procedures, including the type of information or record that may be shared, who the data may be shared with, and release requirements. A Desk Guide is currently used in Los Angeles County.

- **Establish in-house confidentiality experts.**
Even with clear county policies and good training, confidentiality questions will still arise. It is valuable to designate individuals or teams of confidentiality experts to assist staff. When questions arise, staff can contact these experts for consultation. Providing this kind of support ensures consistency within the program, allows responsibility for decision making to be shared in difficult cases, and protects client's rights.

Table 3
**Fresno County Human Services System
Partnership with County Counsel
for Confidentiality Expertise**

When the Fresno County Department of Children and Family Services was establishing its multidisciplinary roundtable teams, the County Counsel was asked to be the legal advisor for the groups to assist in development of consent forms and procedures. The County Counsel attorney took the lead in developing and updating forms and policy for the roundtable teams. When procedures were in place, the attorney took the lead in training the teams. Based on the number of questions raised by staff during training, it was evident that confidentiality was a complex topic of great interest.

This process was so successful that the Director of the Human Services System became interested in establishing a system-wide confidentiality policy and training program for all staff. County Counsel was asked to take the lead and has been proactive in establishing and providing training to all new staff on a regular basis, in addition to training experienced staff in their respective areas. At the time that the Human Services System was created, the County Counsel's office assigned specific attorneys to each department, rather than having all of the attorneys handle issues from each department. This has allowed those individuals the opportunity to become experts in assisting each department with their agency-specific issues.

2. Educate Clients on Their Right to Confidentiality.

The right to privacy, one of the fundamental privileges guaranteed to each citizen by the United States and California constitutions, must be protected at all times. Rules of confidentiality are designed to provide protection to children and their families and to allow them freedom to choose with whom they will share private information. Informed consent preserves the ability of the family to make decisions without apprehension about how its personal information will be used.

Addressing the family's mistrust of the system and fear of having their children taken away is paramount to the coordination of CalWORKs and CWS. Families may be reluctant to share information or even to agree to coordinated services if they believe they will lose custody of their children over issues such as mental health, alcohol and drug problems, or domestic violence. It is essential to convey to families a complete understanding of the purpose of sharing information, the ways in which information may be shared, and the benefits of that sharing. The benefits of educating families about confidentiality are identified in Table 4.

Table 4
Benefits of Educating Families about Confidentiality

- Families will be more willing to share sensitive information.
- Families will be encouraged to participate in potentially stigmatizing programs such as mental health assessments and HIV testing.
- Family-centered decision making will be more likely.
- There will be increased trust between the client and agency.
- There will be professional and respectful treatment of clients.

A variety of strategies can be utilized to achieve these benefits.

- Provide FAQ sheets for clients.
 - Show videotapes in agency waiting rooms.
 - Provide brochures.
 - Include confidentiality information in agency orientations.
 - Discuss confidentiality at intake interviews.
 - Make release forms specific.
- **Provide FAQ sheets for clients.**
A Frequently Asked Questions (FAQ) informational handout about confidentiality should be developed and made available to clients. The county agency could develop the handout to address the specifics about confidentiality concerns and procedures within the county. This is a non-threatening technique that is effective in disseminating information on a sensitive subject.
 - **Show videotapes in agency waiting rooms.**
Many agencies set up informational videotapes on a variety of subjects in their waiting areas for the purpose of educating clients. General information about confidentiality can be prepared for video use in waiting areas.
 - **Provide brochures.**
Confidentiality brochures should be available at all participating agencies. The brochures need to educate clients about confidentiality agreements in general, as well as about how the agreements apply to specific services, such as public assistance, CWS, domestic violence, substance abuse, etc.

- **Include background on confidentiality agreements in agency orientations.**
Many social services agencies ask clients to attend orientations regarding the services they provide. The topic of confidentiality should be one of the items routinely addressed and discussed at these orientations. This approach offers a practical and non-threatening method of delivering information to a large group of individuals at one time. It also indicates the agency's high level of commitment to honoring confidentiality of the client.
- **Provide confidentiality information during intake interviews.**
The close interaction between the caseworker and the family offers an important venue for the provider to explain the benefits and ramifications of confidentiality. The concept of sharing information on a need-to-know basis must also be explained.
- **Make release forms specific.**
Clarity in the release form is critical. The release must conform with the guidelines set forth in the *Model Form for Consent* provided by the Youth Law Center which specifies the necessary elements for a release (see Appendix A). For the family who will be releasing confidential information, it must be clear to them what information is to be shared, how it will be used, and that consenting to release of information is *not* a condition to receive services.

3. Involve and Inform Community-Based Organizations.

CBOs and advocacy groups work with the county, families, and other social services agencies. Because of this, they must be informed of and familiar with of the county's confidentiality guidelines. The Work Group identified several strategies to help counties work constructively with CBOs on confidentiality issues.

- **Fully brief CBOs on the county's confidentiality protocols and materials.**
CBOs can provide valuable assistance to county human services agencies by joining with them to educate clients about confidentiality agreements and to address client fears or concerns. Consequently, these agencies must be fully briefed on the county's confidentiality protocols and be supplied with all of the information that counties have available in this area.
- **Include CBO staff in county confidentiality training sessions.**
Including CBO staff in confidentiality training sessions provided for county staff is a valuable way to ensure that all providers are fully trained.
- **Include confidentiality as an agenda item in regular meetings with CBOs.**
Having confidentiality as a standing discussion topic in quarterly meetings with CBOs is also helpful in building both knowledge base and trust, as well as in providing an opportunity to share vital information about concerns.

END NOTE

Through their research and interviews, the Data Systems and Confidentiality Work Group determined that confidentiality protocols *already exist* to safeguard privacy concerns *and* allow respectful transfer of information among caseworkers. For counties where coordination of services could be improved through clearer confidentiality protocols, county leaders have many strategies available to educate and train staff, educate clients, and inform and involve community-based partners.

APPENDIX A

MODEL FORM FOR CONSENT TO EXCHANGE CONFIDENTIAL INFORMATION AMONG THE MEMBERS OF AN INTERAGENCY COLLABORATIVE

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**Youth Law Center
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MODEL FORM FOR CONSENT TO EXCHANGE CONFIDENTIAL INFORMATION AMONG THE MEMBERS OF AN INTERAGENCY COLLABORATIVE

INTRODUCTION

This model form is designed for use in interagency or multidisciplinary collaboratives serving families and children in California. Its purpose is to provide a mechanism for obtaining valid consent to exchange confidential client information among the participants in the collaborative. (A separate release is necessary for disclosure of confidential information to an agency or individual outside the collaborative.) The model form contains the elements of a valid written consent to release confidential information. These elements are drawn from federal and state laws and regulations, and incorporate the strictest legal requirements of confidentiality and consent provisions governing services to families and children. Thus, the form can be tailored for most collaborative settings, regardless of the number or types of services offered.

The first section of this document outlines general principles and practice tips for obtaining valid consent to share confidential information among the members of a collaborative. The second section identifies the necessary elements of a valid release. These sections are followed by a sample consent form that collaboratives can tailor to meet their specific needs.

GENERAL PRINCIPLES AND PRACTICE TIPS

- **The members of the collaborative should enter into a formal agreement.** Serving families and children through interagency or multidisciplinary collaboration necessitates a careful planning process. Typically, these collaboratives bring together members of different professions or disciplines and employees of different agencies or organizations. Each profession and organization has its own culture, norms, and ways of conducting business. Experience has shown that professions and organizations have distinct approaches and practices related to the exchange of confidential information. These differences are partially attributable to the different laws, regulations, and internal policies concerning confidentiality that govern specific professions or organizations. At the outset, members of a new collaborative need to discuss these issues in order to identify differences, anticipate problems, and develop processes to meet the needs of the different participants and to provide efficient and appropriate services to clients.

One goal of the planning process is to develop a formal agreement or Memorandum of Understanding (MOU) among the participants in the collaborative. At a minimum, the MOU should specify "content" issues, such as the purpose of the collaborative; the organizations, agencies, or individual providers participating in the collaborative; the services provided by the collaborative; the types of client information that will be disclosed among members and the clients who will be served by the collaborative. The MOU should also tackle "process" issues, such as outreach, intake, record keeping, case management, confidentiality, and the exchange of client information among the members of the collaborative.

The process of defining the parameters of the collaborative and the manner in which it will operate is crucial to the success of the project. The resulting MOU memorializes the consensus reached by the group and serves as a reference document for participating service providers, other providers who may wish to refer clients, community members, funders, and others who have an interest in the collaborative. Moreover, when the members of a collaborative understand its purpose and how it operates, they do a better job describing these issues to clients.

- **The members of a collaborative may not exchange confidential client information without proper authorization.** A common misconception is that when an interagency or multidisciplinary collaborative is formed, its members automatically have authorization to freely exchange confidential client information. This is not so and may require clarification. Generally, the employees of an agency or organization may exchange confidential information internally about clients they are serving. However, a collaborative is composed of several agencies and organizations, and confidential client information may not be disclosed among the participants in a collaborative without specific authorization.

Authorization for the exchange of information within a collaborative may come in the form of a statute, court order, or valid consent to release information. For example, the California Legislature has adopted at least two statutes that permit specific types of collaboratives to exchange specific types of client information without a release. By far the most common mechanism for exchanging client information among the members of a collaborative is by obtaining valid consent from the client.

- **Members of the collaborative should only maintain or exchange the information necessary to appropriately serve the client.** The client information collected and recorded should be limited to that genuinely necessary to fulfill the goal of serving the client. This principle is especially important when data is computerized. Seemingly limitless computer memory capacities may encourage staff to collect and record all "interesting" information, whether or not it relates to program goals. By the same token, staff should not automatically disclose the entire client file to another member of the collaborative. Rather, the information exchanged should be limited to that necessary for the recipient to serve the client.

- **A release is necessary for verbal exchange of confidential information as well as exchange of written or automated records.** Many people have the misconception that a signed written release is only necessary for the exchange of written records. In fact, most confidentiality provisions govern the exchange of all confidential information -- regardless of its form. A written release is also necessary to authorize verbal exchange of information.

- **Consent to release confidential information must be informed and voluntary.** In addition to the elements set out below, consent to the release of information must also be voluntary and informed to be valid. The person signing the release must be able to understand what information will be disclosed, to whom it will be disclosed, the purpose of the disclosure, and the benefits and risks of disclosure. In order to make sure that the client understands the risks of disclosure, staff should describe the possible negative consequences of releasing information. For example, a client should understand that disclosing conduct that could be considered child abuse may trigger a legal obligation to report the information to Child Protective Services.

A release is invalid if it is signed by someone who cannot understand the contents of the release -- whether because of mental incapacity, language, or other reasons. Similarly, a release signed under coercion or pressure is not valid; consent must be provided voluntarily. Clients should also understand the consequences of not signing the release. For example, if the client is not willing to disclose her substance abuse, she may be ineligible for services designed for drug-addicted mothers.

RELEASE OF INFORMATION: NECESSARY ELEMENTS

The following elements should be included in any form used to obtain consent to exchange confidential client information among the members of a collaborative. Each of the elements of the release is followed by comments that explain its relevance and how it can be tailored to meet the specific needs of a particular collaborative. The letters of the elements are highlighted on the model consent form on page 7.

(A) Name of the person who is the subject of the information

Comment: This element requires identification of the person to whom the confidential information pertains. When the information to be disclosed pertains to a child, the child's name should appear here even though he or she may not be legally competent to sign the release. There should be a different release for each individual, including children in the same family.

(B) Names of the persons/organizations in the collaborative authorized to share confidential client information

Comment: This element requires identification of the individuals or organizations who are permitted by this release to exchange client information. The client's privacy rights are best protected by specifying and limiting as much as possible the persons authorized to disclose confidential information. Potential for mistakes or mishandling of confidential information increases with the number of people who have access to, and control the exchange of, confidential information.

Thus, even where several organizations are affiliated with a collaborative, the staff person conducting the intake should tailor the release as closely as possible to the services requested or needed by the specific client. In other words, the release should not contain a boilerplate list of participating persons or organizations that has no connection to the services needed by the particular client. Rather, the release should identify only those persons or organizations who may require confidential information to serve the specific client.

(C) Type of information exchanged

Comment: The release should notify the client of the types or categories of information that may be exchanged. Again, the description should be as specific as possible. For example, "all client information" is too general because it does not give the client adequate notice of the types of information that may be disclosed. "Mental health information" is better, but is still quite general. It is best to spell out what kinds of mental health information, such as history, diagnosis, hospitalizations, medication, mental health provider, etc.

The staff person explaining the consent process to the client should make clear that the client may consent to the release of certain information, and withhold consent to the release of other information. The written release should reflect these choices. For example, the form might provide a space for the client's initials beside each type of information; the client can initial those categories of information that he or she agrees may be disclosed and cross off the categories of information he or she does not want disclosed. These options may not be immediately apparent to the client, and staff should carefully explain them. The manner in which the consent process is explained to clients is just as important as the contents of the written consent form. Staff must be well trained to understand the process of obtaining valid consent to release confidential information.

(D) Reasons for sharing the information

Comment: A release should indicate the circumstances that would trigger disclosure of confidential information. Confidential information should only be disclosed when necessary to provide comprehensive services to the client. Thus, the reason for sharing the information should be connected to the purpose of the collaborative. For example, if the purpose of the collaborative is to provide family preservation services, the release should indicate that confidential information will only be released among members of the collaborative when it is necessary to provide family preservation services to the client.

(E) A statement prohibiting redisclosure without consent

Comment: The consent form should contain a statement that any person or organization in the collaborative that receives confidential information pursuant to the release will keep the information confidential and will not redisclose the information outside the collaborative without a valid release to do so. A good practice is for the members of the collaborative to enter into an agreement (often called a Memorandum of Understanding or MOU) that prohibits the members from redisclosing confidential client information.

(F) A statement that the signer has the right to revoke the consent to release information

Comment: The person who is authorized to sign a consent to release information also has the authority to revoke that consent at any time. The best practice is to include a statement to that effect on the release, and to verbally explain the statement to the signer. Staff should also explain the process by which the client can revoke his or her consent. For example, the procedure could require the client to sign and date a written revocation form devised by the collaborative. Such a form should contain a simple statement, such as, "I hereby revoke my consent to the disclosure of any confidential information by the ABC Collaborative."

(G) A statement that the release expires upon the occurrence of a specific event or on a specific date

Comment: Limiting the operation of the release to a specific period of time is an important means of protecting the privacy rights of the person who is the subject of the release. Specifying a time limit guards against general releases whose application is too broad, and contributes to the process of identifying a specific purpose for disclosing the information. If, upon the expiration of the original release, there is still a need to exchange confidential information, the appropriate staff person should prepare a new release tailored to the current needs of the client and obtain the necessary signature. If the release expires upon the occurrence of an event, such as the end of the school year, that event should be easily identified by the client and by the collaborative.

(H) A statement that the subject has a right to a copy of the release

Comment: The subject of the release (or authorized signer) should receive a copy of it. This practice helps to ensure that the signer knows and understands the contents of the release. The release should specifically state that the subject (or authorized signer) is entitled to a copy of the release. This practice helps to establish that the subject or signer was aware of his or her right to a copy.

(I) Date the release is signed

Comment: It is important to date the release so that it is clear when it becomes effective. When the release expires after a specific period of time (e.g., one year), the date the release is signed is also necessary to compute the date it ceases to be operative.

(J) Signature of person who is the subject of the information or his/her legal representative

Comment: The general rule is that the person who is the subject of the release must sign it. An important exception to this rule is when the subject of the release is legally incompetent to consent to release of confidential information. For the most part, minors are legally incapable of providing consent for services or for the release of confidential information. Thus, the child's parent, guardian, or responsible adult must sign the release.

There are some circumstances under which minors may consent to services. Emancipated minors are legally competent to provide consent without parental consent, knowledge, or liability. Minors are emancipated if they are married or on active duty in the armed forces, or if they have received a declaration of emancipation from the court. Before a minor can be emancipated by the court, he or she must meet the following requirements: 1) the minor is at least 14 years of age; 2) the minor willingly lives separate and apart from his or her parents or guardians with their consent or acquiescence; 3) the minor is managing his or her own financial affairs; and 4) the source of the minor's income is not derived from any illegal activity.

Minors who are at least 15 years old, living separate and apart from their parents, and managing their own financial affairs may consent to any medical and dental care. Finally, certain minors may consent to certain "sensitive" or "confidential" medical services without their parents' consent or involvement.

The authority to provide consent for the release of confidential information derives from the authority to provide consent for services or care. Thus, if the minor has the legal authority to consent to the services, he or she also has the legal authority to provide consent for the release or disclosure of information related to those services. In fact, parental consent is insufficient in these circumstances. Conversely, if parental consent is necessary to provide the services, parental consent is also necessary to permit disclosure of information related to those services.

For children who are wards or dependents of the juvenile court, parents maintain authority over records concerning their children unless the court specifically removes that authority and delegates the responsibility to another person -- such as a social worker, foster parent, facility administrator, etc. Thus, staff members should obtain the necessary consent for services or for release of information from parents unless the parents are unavailable or the court has identified another responsible party. The court itself may also provide the necessary consent for services or release of information.

**MODEL FORM FOR CONSENT TO EXCHANGE CONFIDENTIAL
INFORMATION AMONG THE MEMBERS OF
AN INTERAGENCY COLLABORATIVE**

I, _____, authorize
Name of authorized signer **(A)**

the following members of the (*name of collaborative*):

Names of the persons/organizations authorized to exchange confidential information **(B)**

to exchange the following information about [*me*] [*my child or ward*, _____]:

Nature of information, as limited as possible **(C)**

The purpose for the exchange of the above information is:

Purpose of disclosure, as specific as possible **(D)**

I understand that (*the members of the collaborative*) will not redisclose the information outside (*name of the collaborative*) without a valid release to do so. **(E)**

I also understand that I can revoke this consent at any time except to the extent that action has been taken in reliance on it. **(F)**

In any event, this consent expires automatically as follows:

Specification of the date, event, or condition upon which this consent expires **(G)**

I understand that I am entitled to receive, and have received, a copy of this signed consent form. **(H)**

Dated: _____ **(I)**

Signature of subject of release **(J)**

Signature of parent, guardian or authorized
representative when required