

Confidentiality and Data Sharing Protocol

Revised May 2009



Children and Families Commission of Orange County

www.occhildrenandfamilies.com

Children and Families Commission of Orange County
CONFIDENTIALITY AND DATA SHARING PROTOCOL
REVISED - May 2009

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I. PURPOSE OF THE CONFIDENTIALITY AND DATA SHARING PROTOCOL

The purpose of this document is to establish the policy to be followed for managing and sharing confidential consumer information and records. This document defines the roles, responsibilities, flow of information, and required documentation for the client consent and contractual relationship between the Children and Families Commission of Orange County (the “Commission”), organizations that receive funding or assistance from the Commission (“Grantees”), the organization or vendor that the Commission hires to maintain and monitor the use of the Commission’s database system (the “Database Vendor”), and Commission evaluation staff and contractors. The Commission’s database system to support evaluation of the services and programs that the Commission funds is known and referred to as the Outcomes Collection, Evaluation and Reporting Service (OCERS). This document also defines the process that all researchers/evaluators must follow to access and use Commission data.

II. THE CHILDREN AND FAMILIES COMMISSION OF ORANGE COUNTY

The Commission was established in 1999 to administer the funds allocated to Orange County under Proposition 10, the California Children and Families Act of 1998 (the “Act”). The Act provided for an excise tax on tobacco products, the proceeds of which are used to fund services that promote, support, and improve the early development of children from the prenatal stage to five years of age. In 2000, the Commission first adopted its Strategic Plan, which outlines its goals, outcomes, indicators and objectives, and guides its funding decisions. The Strategic Plan is updated annually and is available on the Commission’s web site.

III. EVALUATION REQUIREMENTS

The Act (codified at Section 130150 of the California Health and Safety Code) requires each county commission to “conduct an audit of, and issue a written report on the implementation and performance of, their...functions during the preceding fiscal year, including, at a minimum, the manner in which funds were expended, the progress toward, and the achievement of, program goals and objectives, and the measurement of specific outcomes through appropriate reliable indicators.”

IV. EVALUATION FRAMEWORK

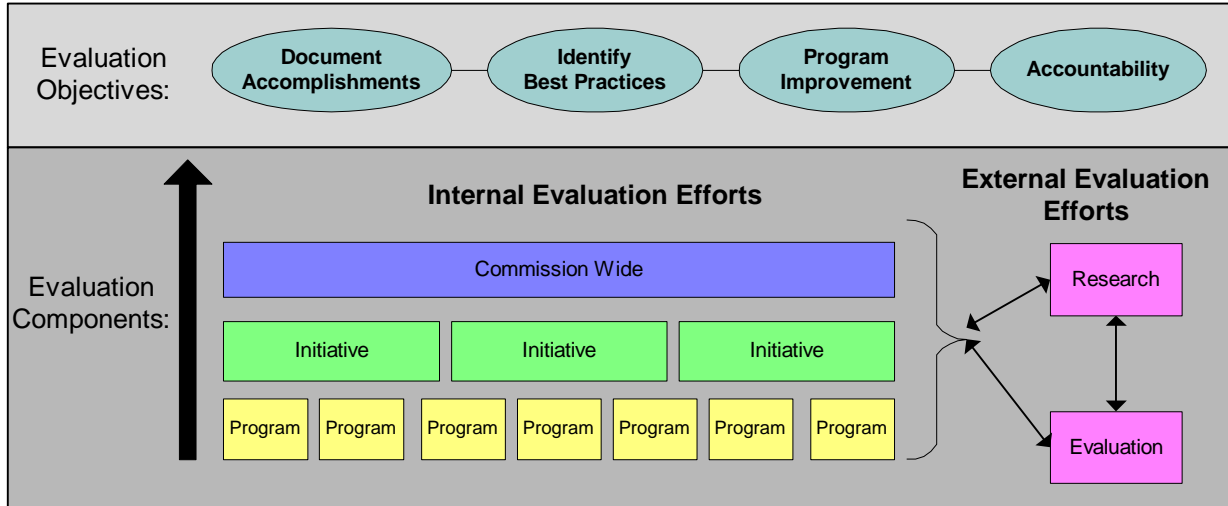
The Commission has adopted a comprehensive evaluation plan that includes both process and outcome measures that are measured in the short, intermediate, and long term. The Evaluation Framework includes both Commission-wide and Program-specific evaluations. In addition, the Commission participates in the development of community-wide data. Evaluation results are communicated through reports that are presented to the Commission’s Directors and its Grantees and posted on the Commission’s web site.

The Commission’s evaluation activities are carried out by the Performance Outcomes Measurement System (POMS) Team. POMS Team members participate on state and regional committees and work groups that share best practices and results. In addition, the POMS Team provides qualitative and quantitative information, and program specific expertise to support the development of strategies to address Commission priorities such as: school readiness, school

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nursing, health access, at-risk children, early literacy, oral health, and community outreach. Figure 1 below illustrates the relationship between the various evaluation components—at the Commission-funded level (internal) and outside the Commission (external)—that the POMS Team carries out, as well as the overarching evaluation objectives.

Figure 1: Relationship between the Commission’s Evaluation Objectives and Components



V. THE OUTCOMES COLLECTION, EVALUATION AND REPORTING SERVICE (OCERS)

The Commission contracts with a Database Vendor to implement OCERS to permit Grantees to report the outcomes of the services that Grantees provide to children prenatal to age five and their families.

The specific objectives of OCERS are to:

- ❑ Provide a secure, Internet-based data collection system to Grantees based on the goals, outcomes, indicators, and objectives in the Commission’s Strategic Plan.
- ❑ Protect consumer confidentiality.
- ❑ Reduce duplication of efforts and enhance reporting of cumulative services by implementing a unique identifier for consumers..
- ❑ Provide for authorization-driven, secure data sharing and reporting across Grantees to track the overall impact of services on children and families over time.
- ❑ Permit data to be reported in an aggregate format for needs assessment, planning, evaluation, and research.

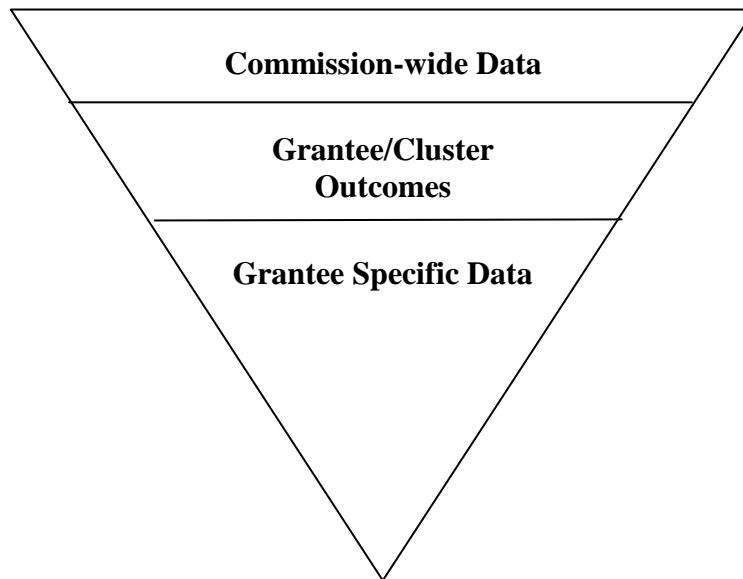
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- Assist Grantees and the Commission with measuring success in achieving outcomes and objectives.

Consumer-specific data collection in OCERS is based on a three-tier approach as illustrated in Table 1:

1. Commission-wide data (See Attachment 1) consisting of consumer identifying information and common outcomes (i.e., consumer demographics, initial outcomes, core data elements) that are collected by Grantees that provide direct services (i.e. not Capacity Building Grantees).
2. Grantee/Group level outcomes, such as service outcome questions (See Attachment 2) that are collected by Grantees with common objectives – collected across one or more Grantees.
3. Grantee Specific outcomes – outcome questions defined and analyzed by an individual Grantee.

Table 1 – OCERS Approach



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The data may be used as follows:

- The Commission may report aggregate information (no individual consumers are identified) from an individual Grantee, a group of Grantees, or across all Grantees.
- Grantees may use their own consumer-identified information for internal purposes only, such as case supervision.
- Grantees may prepare and disseminate reports of their own aggregate data for use in program planning and reporting to other stakeholders.

VI. SUBJECTS – CONSUMERS

A. Selection of Participants

Consumers who are served under Commission contracts may participate in the data collection efforts voluntarily. Depending on the Grantee program, and with Commission approval, there may be selection of consumers to participate based on the intensity of services provided or on random sampling. In no event will the services available to the consumer be affected by their decision to participate or not participate in this data collection. Consumers served will include Orange County children from prenatal to age five and their families through the children's parents. Additional legal representatives of the consumer may include a consumer's primary caregiver(s), relative caregiver(s), guardian or other significant adult such as a foster parent.

B. Guiding Principles

The following criteria will apply when including consumer information in OCERS or other Commission-related evaluation databases:

1. An informed Participant Authorization Form (see Appendix 1) will be completed to permit the sharing of consumer information with the Commission and Commission representatives.
2. There will be no consumers selected for control groups or experimental procedures unless the protocol for doing so has been approved by the Commission and the Institutional Review Board(s) of the participating agency(ies).
3. Consumers will not be paid in any form for their participation. However, consumers may receive incentives, such as stipends or gift cards, for participating in Commission-related evaluation activities.
4. Care/services will be provided, where appropriate, by any service provider legally authorized and charged with providing such services under its contract with the Commission.

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5. Each Grantee will be responsible for carefully monitoring the data collection, storage and reporting of consumer related information. Each Grantee will follow the Commission's written Confidentiality and Data Sharing Protocol when including consumers in OCERS or other Commission-related evaluation databases.
6. Reports generated will provide only aggregate-level data; individual consumers will not be identified.

C. Risks/Discomforts/Inconveniences to Consumers

All Commission evaluation processes will disclose risk and discomforts to consumers. There are projected to be only minor risks, discomforts or inconveniences for the children and families served within Commission-funded projects covered by OCERS. The primary risk is the inadvertent disclosure of private information. The Commission, its partners, and its Grantees follow policies and procedures designed to protect consumers' private information. All consumers served will be asked to freely provide their informed authorization to release confidential information about themselves and the services they received. Services will not be denied if a consumer, parent, or legal representative of a consumer does not agree to allow their identifying information to be collected for outcomes reporting purposes.

D. Benefits to Consumers

The Commission evaluates the programs it funds to learn about their accomplishments and the changes they are making in the lives of the consumers they serve, to guide program improvements, and to comply with the statutory requirements. Through the Commission's investments, it is anticipated that the consumers will be provided early screening, focused intervention and coordinated family support services to assist in better preparing the children for school. The purpose of OCERS is to provide the Commission and its Grantees with an efficient and secure means of collecting and reporting the outcomes of services provided to consumers, which include children prenatal to five years of age and their families. The experience gained and the data recorded on behalf of consumers will enable the Commission to better target its resources using best practices.

VII. CONSUMER RIGHTS AND RESPONSIBILITIES

Only legally authorized representatives of the consumer, whether parents or representative caregivers, who are responsible for the care of the consumer, may approve access to or release of confidential information and records related to the consumer, including pertinent family information. In addition, consumers who are minors may authorize access to or release of their confidential information and records once they have obtained the capacity to act on their own pursuant to law.

For a legal representative of the consumer to represent the consumer's best interests, he or she must be properly informed of his or her rights and responsibilities and those pertaining to the consumer. This includes information regarding the sharing of confidential consumer or family

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information among Commission Grantees and partners, and how this information will be used and secured.

Legal representatives of consumers who agree on their behalf and on behalf of the consumers to participate in Commission-funded services will be asked to provide personal and uniquely identifying information that will be included in OCERS. Legal representatives of consumers must indicate, through the Participant Authorization Form, their understanding and willingness to participate in this data-sharing effort. If the legal representatives' ability to adequately understand and make decisions regarding their participation and the participation of consumers in Commission-funded services – due to age, cognitive impairment, extreme stress, or other factors – is uncertain, then a legally authorized representative may make the decision regarding such participation.

By law, confidential information about a consumer may be released without specific authorization only if Grantee staff has reason to believe that the consumer is in imminent danger to himself or herself or to others; or if the consumer is an alleged victim or perpetrator of child, elder, or dependent abuse.

The following personally identifiable information will not be collected or shared without the explicit written authorization of the consumer or legal representative of the consumer:

- Name, date and place of birth, gender, ethnicity, primary language, current address, services received, results of the services received
- Medical information (medical/dental care utilization, birth weight, immunizations, etc.)
- Health diagnosis and treatment.
- Educational information (preschool services, special needs services, etc.)
- Developmental information (developmental screening, assessment, and services)
- Participation in alcohol or drug treatment programs.
- Criminal arrests or convictions.

Clients are not asked to report on their participation in alcohol or drug treatment programs or their criminal arrests or convictions. The explicit written authorization for the gathering and sharing of personally identifiable information is requested from the client through the Participant Authorization Form (Appendix 1).

If the consumer receives services that are provided in conjunction with a research project, the consumer may be asked to sign an informed consent giving permission to participate as a human subject. This form would be in addition to the Participant Authorization Form.

Information regarding a consumer's citizenship status may be shared among Grantees only when this information is required to certify eligibility for programs and the consumer has requested assistance related to his or her eligibility determination. Information on citizenship will not be entered into OCERS.

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The authorization to release confidential information provided through the Participant Authorization Form will be effective until the nineteenth birthday of the consumer who is a minor. Written authorization may be revoked at any time by (1) the legal representative or other legally authorized person or (2) the minor consumer – once he or she has obtained the capacity to act on his or her own pursuant to law. Action taken prior to the revocation of the authorization to release confidential information may not be revoked.

One copy of the Participant Authorization Form must be provided to the consumer or legal representative when the consumer or legal representative signs the authorization and a second copy must be kept in paper or electronic record by the Grantee. Consumer data may not be accessed without a signed authorization from the legal representative of the consumer (see section X. Access To and Use of Data by Evaluators/Researchers).

The portion of consumer records maintained in OCERS that contain personally identifiable information will only be available to parties who are contracted to provide Commission services to the consumer and to the Database Vendor solely for the purpose of database management. Non-identifiable or aggregated data based on records stored in OCERS will be made available as approved for access by the Commission to those conducting needs assessments, planning activities, evaluation, Grantee audits, or research related to the children and families of Orange County who are participating or have participated in Commission-funded services. The Database Vendor, through OCERS and its related modules, will provide for the protection of consumer confidential information with the most advanced security technology available, and will meet all applicable Federal Privacy Regulations (i.e., 45 CFR Part 46, 45 CFR 160 and 164 [HIPAA Regs.], 42 CFR Part 2, etc.)

VIII. RESPONSIBILITIES OF GRANTEES AND THE COMMISSION

In addition to fulfilling the requirements described under Consumer Rights and Responsibilities, each Grantee staff member obtaining written authorization to release confidential information will fully explain to the persons concerned the confidentiality policy and procedures, the participant authorization form, and the activities that will be undertaken on the consumer's behalf.

The responsible staff person will make sure that an orientation is provided in a language that the consumer and/or the legal representative can fully understand. The responsible staff person will further respond fully, appropriately, and in a timely manner to the questions and concerns of the consumer and/or legal representative related to the forms or the confidentiality policy and procedures. If an adequate orientation in the consumer's language is not possible, the consumer should not be asked to participate in the data collection efforts.

If the legal representative of the consumer does not speak English, or cannot adequately read English or another language, then it is the responsibility of the Grantee as an organization, and its individual staff collecting the information, to provide an interpreter, or to read the form to the consumer or legal representative, and to sufficiently explain to them any difficult wording.

A. Grantee Performance Standards

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Provision of full information to the consumer or the legal representative of the consumer on collection of data, data sharing and confidentiality, as well as on services, to enable the consumer or representative to have a full understanding of Grantee confidentiality policies and protocols, is part of the Grantee's performance standards. Any violation of the Commission's Confidentiality and Data Sharing Protocol that involves a consumer's confidential information and records may be grounds for contract revision or termination and may expose the violator to civil and/or criminal penalties.

B. Grantee Environment for Data Collection and Storage

Grantee staff will assure that:

- 1) Oral communication between Grantee employees and the consumer or legal representative of the consumer cannot be overheard in the interview setting by unauthorized staff, other program participants, or visitors;
- 2) Written communications pertaining to a consumer's case are not accessible to unauthorized staff, other program participants, or visitors;
- 3) Its employees or authorized staff ask the consumer or legal representative of the consumer about the comfort level of the interview setting as related to the consumer's confidentiality. Grantee staff will accommodate a request for a more private interview setting.

C. Protecting Consumer Records

In order to ensure the safekeeping of consumer records containing confidential information about the consumer, and at the same time provide for record maintenance, quality control, and monitoring/evaluation activities, the following procedures will be followed:

1. Storage of Consumer Records

The original, signed copy of the consumer's Participant Authorization Form – and any other information regarding the consumer collected at any point in time on paper, printed from electronic files, or stored electronically – will be placed in a personal paper or electronic file folder, and stored in a location accessible only to authorized personnel (with consumer consent) or to Grantee staff who have signed the User Confidentiality Agreement (Appendix 3). Contents of the consumer's folder or hard copy or electronic confidential information will only be shared with authorized representatives (employees, consultants, evaluators, contract monitors, etc.) of other Grantees, the Commission, or the Database Vendor, to whom the consumer has released the specific confidential information described on the Participant Authorization Form or another appropriate release form. Once the consumer's data has been entered into OCERS, Grantee staff may destroy the hard copies of the data forms as the data can be retrieved through OCERS reports. However, Grantees must keep copies of the Participant

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Authorization Form for a minimum of three years after their contract with the Commission has terminated. Additionally, Grantees may be required to retain some client records (e.g., patient medical records) longer to comply with other state or federal regulations.

All ACTIVE and/or INACTIVE consumer records will be overseen by an authorized administrator chosen by Grantee or Commission staff for this task. INACTIVE consumer records will be maintained by the same Grantee or Commission designee.

2. Exclusion and Purging of Automated Records

Refusal to authorize the release or sharing of confidential information shall not affect the consumer's receipt of services from Grantees, now or in the future.

Should at any point in time the consumer or the legal representative of the consumer decide to have the consumer's records purged from the database, they may do so by contacting the Grantee or the Commission in writing. All records containing information on consumers seeking to remove their information from the database will be purged in a manner consistent with the consumer confidentiality rights that are described above. See Appendix 2 for a form to be used to request removal of confidential information from OCERS.

D. Staff Training

Upon the adoption of this or other authorized Protocol, Grantee staff will receive training on the protocol, policy, and procedures for the release of confidential information contained in manual and automated information systems as it relates to Commission-funded programs. Training will be provided for by Commission staff and/or through contracts with the Commission.

E. Adherence to Legal Requirements

In addition to the safeguards above, all parties who participate in data-sharing with Grantees, the Commission itself, Commission contractors and staff, evaluators, and the Database Vendor, are required to comply with all applicable laws, regulations, grant agreements, and contractual conditions pertaining to the receipt of funds from the Commission directly, or indirectly through other public agencies or departments of the County of Orange. To facilitate this requirement, Grantees will be required, through the contract with the Commission, to develop a written, internal confidentiality protocol or review the Grantee's existing protocol that mirrors and supports that of the Commission.

F. Policy Questions

All policy issues related to confidentiality will be directed to the Privacy Officer of the Commission or the Grantee staff person designated as the OCERS contact in the Grant Agreement with the Commission.

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IX. INTERAGENCY INFORMATION EXCHANGE

The Commission encourages Grantees to work together and coordinate services provided to consumers. This often results in consumers receiving services from more than one Grantee. Consequently, Grantees need to be able to share information about consumers to streamline service delivery and avoid duplicate data collection for OCERS. The two purposes of information sharing – *service delivery* and *data collection* for OCERS as well as other evaluation efforts– should be viewed and treated separately.

Sharing information to facilitate service delivery should be governed by formal relationships between / among the Grantees serving the consumer. Grantees should develop written protocols and/or agreements such as Memorandums of Understanding (MOUs) with other Grantees to specify what information can be shared and under what circumstances. Such protocols and/or agreements should be approved by each Grantee’s governing body or other authorized officer or official. Furthermore, Grantees should consult with their legal counsel for compliance of such protocols and/or agreements with all legal requirements governing these formal relationships, such as the HIPAA Regulations and other applicable state or federal regulations applicable to the sharing of private consumer information.

The sharing of consumer related information is governed by the Commission’s written Confidentiality and Data Sharing Protocol. Before viewing and entering consumer information in OCERS, the Grantee must have complied with all aspects of the Commission’s Protocol, such as to have a signed and dated Authorization from the consumer or consumer’s legal representative. Grantees working in partnership may develop a single authorization form that identifies all partner Grantees so that the consumer needs to only sign one authorization form. Each Grantee of the partnership should keep a paper or electronic record of the signed authorization.

X. ACCESS TO AND USE OF DATA BY EVALUATORS/RESEARCHERS

In order for a data system to be useful, the data entered must be retrieved, analyzed and reported. Such reports can provide valuable information about the consumers, the services provided, best practices, and gaps in services.

A. Access and Use of OCERS Data

All evaluators/researchers who wish to access data in OCERS must sign a Memorandum of Understanding for Evaluator/Researcher Access to and Use of OCERS Program Data with the Commission or a Grantee (see Appendix 5). Data provided to evaluators/researchers may have unique identifiers (e.g. AB99 elements), but will not include any personally identifying information.

Data extracted from OCERS may be used only to satisfy contracted deliverables and program management unless a research exception is granted. To obtain a research exception, a written

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request to access OCERS data should be submitted to the Director of Program Development and Evaluation (17320 Redhill Ave., Suite 200, Irvine, CA 92614) and must include:

- A description of the hypothesis-driven project that will be addressed using OCERS.
- A copy of the protocol approved by a registered Institutional Review Board (IRB), along with evidence that the protocol was approved.
- A description of the data fields in OCERS required to complete the project.
- A description of how the data will be analyzed.
- A description of how the analytic results produced by the project will be reviewed and disseminated.
- A description of the evaluator/researcher's qualifications to complete the work.
- The time period for which access is requested. Approval to use OCERS data will only be granted for a specified period of time.

The request will be reviewed by the Commission's Evaluation Review Committee, a 5-7 member committee established by the Commission's Executive Officer. At a minimum, the membership may include the Commission Evaluation Manager, an Evaluation Consultant to the Commission, a member of the Commission Technical Advisory Committee, a representative for the CHOC/UCI Collaborative, and a representative of the School Readiness Initiative. Additional reviewers may be invited depending on the subject matter of the proposed evaluation. The committee will apply the following criteria when considering requests to use OCERS data:

- The extent to which the findings of the proposed research/evaluation project will benefit children prenatal to five years of age
- The extent to which the data analysis will support scientifically valid reporting of the data
- The person(s) requesting use of the data are qualified to complete the proposed project
- The results of the research will be disseminated in appropriate formats and forums, including refereed scientific journals, professional meetings, and/or presentations to the Commission and its Grantees

B. Access and Use of Non-OCERS Data

Evaluators/researchers who wish to collect and/or access non-OCERS data must ensure the same high level of confidentiality as outlined in this protocol. Examples of non-OCERS data include, but are not limited to, creating and conducting surveys, focus groups, educational assessments, and/or individual interviews, and linking OCERS data with non-OCERS data. It is the responsibility of evaluators/ researchers to verify whether IRB approval is necessary (see: Section X-C) and whether any additional consents/releases are required.

C. Institutional Review Board (IRB) Approval

The Commission reviews its Confidentiality and Data Sharing Protocol and all OCERS data collection tools annually; makes updates as necessary; and submits it to the Human Subjects

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Review (HSR) for County IRB review and approval. Evaluators/researchers who wish to use OCERS data in a way not specified in this protocol may need to go through IRB approval. To confirm whether approval is needed, refer to the Health & Human Service's Office for Human Research Protections (OHRP) decision charts located at the following web site:

<http://www.hhs.gov/ohrp/humansubjects/guidance/decisioncharts.htm>

XI. DEFINITIONS

For purposes of this protocol, the following definitions apply.

A. Consumer

The consumer is a child prenatal to five years of age and/or a child prenatal to five years of age's family member, who is identified by the Grantee as in need of services, and about whom data will be entered in OCERS.

B. Confidential Information

Data regarding a consumer that are shared among Grantee staff and obtained through written or verbal communication with the consumer, or by reviewing confidential consumer records in manual or automated format.

C. Core Data Elements

The data elements, including personally identifiable information, in OCERS that will be entered by Grantees regarding consumers identified as receiving Commission-funded services (see Attachment 1).

D. Service Outcome Questions

A series of questions that are asked about a consumer after a Grantee has finished providing services to the consumer (See Attachment 2). The service outcome questions provide outcome measures for Commission-funded services. Responses to the service outcome questions are completed by Grantee staff and entered for individual consumers, but are reported only at the aggregate level.

E. Personally Identifiable Information

Information regarding a consumer that allows those with access to the information to determine the consumer's identity. It includes the consumer's name(s), birth date, place of birth, gender, and name(s) of other family members.

XII. REQUIRED FORMAT OF DOCUMENTS

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Required formats for the following documents are attached for use by Grantee staff to assure that the exchange of information and records adequately addresses the confidentiality and informed consent needs of consumers. Use of some of the required formats may be waived through contract between the Grantee and the Commission if the responsibilities and intent of the contract are addressed through the Grantee's existing protocols and procedures.

A. Participant Authorization Forms (Appendix 1)

The Children and Families Commission of Orange County's "Participant Authorization Form" allows for common language and documentation of the informed consent necessary when consumer information is entered into OCERS and shared through any medium, including in-person, phone, fax, mail, carrier service, email, or via OCERS. The signed form permits Grantee staff to review, discuss, and exchange copies of information on common consumers from OCERS automated and other related files and confidential records, if both Grantees have obtained a signed Authorization. It provides the responsible legal representative of the consumers with information regarding the purposes and limits for data sharing and outlines the specific information for which the consumers are authorizing release.

B. Request to Remove Confidential Information from OCERS (Appendix 2)

Consumers can revoke the signed Participant Authorization Form at any time either by signing a Request to Remove Confidential Information from OCERS form or by submitting their request in writing. The request should be submitted either to the Grantee that obtained the original authorization or to the Children and Families Commission of Orange County. Consumers who revoke their authorization will still receive all needed services for which they are eligible. Use of the data after authorization and prior to the request to remove data cannot be revoked.

C. User Confidentiality Agreement (Appendix 3)

The User Confidentiality Agreement (either for Grantee Staff or for Commission Staff and Consultants) should be signed by all present and future employees of Grantees, Database Vendor, and the Commission who will have access to consumer data entered into the OCERS system. It documents that they understand and will abide by the confidentiality protocols of the Grantee and the Commission. This agreement includes the responsibilities and liabilities resulting from the inappropriate, unauthorized, or illegal disclosure of consumer information to which they have access as part of a Commission-funded project or program. The person executing the User Confidentiality Agreement also agrees not to redisclose any confidential consumer information to which they have access to any other party without the express, written authorization to release the confidential information from the consumer or the consumer's parent, guardian, or legally authorized representative.

D. Prohibition on Redisclosure (Appendix 4)

The Prohibition on Redisclosing Information Concerning Consumers Receiving Services is a notice that must accompany any manual or automated exchange of data between Commission

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Grantees. It warns against the inappropriate, unauthorized, or illegal disclosure of the confidential consumer information – or the redisclosure of any confidential information – and shall be attached to all paper or electronic copies of data shared as part of a Commission-funded project or program.

E. Memorandum of Understanding For Evaluator/Researcher Access to and Use of OCERS Data (Appendix 5)

The Memorandum of Understanding for Evaluator/Researcher Access to Data and Use of Program Data is an agreement between a Grantee or the Commission and an evaluator/researcher hired or assigned by the Grantee or Commission to evaluate projects funded by the Commission using data in OCERS.

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Appendix 1

(Note: Print the following in 14-point font on organization letterhead or other format with organization name)

Participant Authorization Form – Primary Caregiver and Child

As the parent or legal guardian of _____
(Child's name as listed on birth certificate) (First) (Middle) (Last)

I agree to allow (*organization*) to share information about me and my child with the Children and Families Commission of Orange County, trusted organizations that are partners with the Commission, and Commission representatives. The information will be used to help the Commission learn how the services it funds help children prepare for school and to help plan for future services.

The information about both me and my child may include the following:

- Name, date and place of birth, gender, ethnicity, primary language, current address, services we received, results of the services received
- Medical information (medical/dental care utilization, birth weight, immunizations, etc.)
- Educational information (preschool services, special needs services, etc.)
- Developmental information (developmental screening, assessment, and services)

SPECIFIC AUTHORIZATIONS:

The following information will not be released unless you specifically authorize it by marking the box below:

- I specifically authorize the release of information pertaining to mental health diagnosis or treatment or psychological information (Welfare & Institutions Code, §§5328, et seq)

I understand that:

- I should answer only those questions with which I am comfortable -- I do not have to answer every question asked;
- Providing the information may involve a 10-minute interview when I start the program, when I complete the program and annually while I am receiving services from this program;
- Reports prepared from this information will not identify me or my child in any way;
- My approval to share this information will end on my child's nineteenth (19) birthday, and the information will be removed from the computer system. I also understand that I may cancel this authorization at any time by submitting a Request to Remove Confidential Information Form or by writing to (*organization*) or the Children and Families Commission of Orange County at 17320 Redhill Avenue, Suite 200, Irvine, California, 92614. My child may also cancel this authorization in writing when he/she is at the age in which the law allows him/her to act on his/her own;

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- Signing this Authorization is voluntary; if I choose not to sign this Authorization, my child and I will still receive services from (*organization*).
- This Authorization does **not** include sharing information that may identify me or my child related to participation in alcohol or drug treatment programs or criminal arrests or convictions. Such information may only be shared if I sign a separate, specific written consent form;
- The security and protection of my private information are very important to (*organization*). The only people who will be able to see my personal identifying information are those that provide me services and the Commission's computer consultants, who need this information in order to delete and/or correct records. The Commission's staff and its partners who have access to our personal identifying information have signed an agreement to maintain its privacy.
- After some health information is shared it may no longer be protected by the Federal Privacy Rule, but it still is protected by other state and federal laws.
- A copy of this consent form will be as good as the original. I know that I have a right to get a copy of this form if I ask for one.

Signature of parent or legal guardian: _____

Date: _____

Please print name clearly: _____

Relationship to child: _____

Child's birth date: _____

FOR OFFICE USE ONLY

Name of Commission Funded Program: _____

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Address _____

Phone Number: () _____ - _____

Please send me a letter telling me that the data has been removed from the system (you must provide a mailing address above)

Person Accepting Petition:	Removal Completed Date:
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Submit this form to your service provider or to:
Children and Families Commission of Orange County
17320 Redhill Avenue, Suite 200
Irvine, CA 92614

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Appendix 3

USER CONFIDENTIALITY AGREEMENT – For Grantee Staff

- All staff, consultants and members of Commission-funded programs and projects (Grantees) who are responsible for gathering, maintaining or accessing confidential information and/or records must read and sign this Agreement.
- After this Agreement has been signed, the original Agreement must be sent to the immediate staff supervisor who must sign the Agreement.
- Once signed, the immediate staff supervisor will file the original Agreement in the Grantee’s personnel files, and return a copy to the other signatory.
- Undefined terms shall have the meaning established in the Confidentiality and Data Sharing Protocol.

The undersigned (User) has been authorized by (*organization*) to have electronic access via the Internet to a database containing consumer data (Consumer Data) maintained by Database Vendor on a secure website. Some of the Consumer Data may be in a personally identifiable format. All Consumer Data, regardless of whether it is personally identifiable, is deemed to be sensitive, proprietary, and confidential. Unauthorized use or disclosure of Consumer Data could have serious adverse consequences for the Children & Families Commission of Orange County (“Commission”), Database Vendor, User, User's employer, and the consumer(s).

User hereby expressly agrees not to use, display, disclose or otherwise exploit (Use) the Consumer Data in any manner, directly or indirectly, for personal, commercial, or financial benefit of any kind, nor to permit such Use by any other person, except as may be necessary for User or User's employer to provide, or facilitate the provision of; services to the consumer(s) whose data is Used; and otherwise in strict compliance with any mandatory guidelines issued by Commission and Database Vendor from time to time regarding access to and Use of the Consumer Data, to which User hereby agrees to be bound.

User acknowledges that unauthorized Use of the Consumer Data could cause irreparable harm and damage to the consumer(s), Grantee, and/or Commission, for which the consumer(s), Grantee, and/or Commission may seek legal remedies. User shall indemnify and hold Commission, its officers, directors, employees, and agents, harmless from any and all costs, expenses, damages, or liability of any kind whatsoever arising from any Use of the Consumer Data by User, or permitted by User, in violation of this agreement.

The Consumer Data is the property of the Commission. Nothing herein shall be construed to grant to User or to User's employer, any ownership or access rights to the Consumer Data except as expressly set forth herein. Commission may terminate the access rights of User to the Consumer Data at any time if, in the sole judgment of the Commission Administration, termination of access is necessary or appropriate to preserve the confidentiality and integrity of the Consumer Data, regardless of whether User has violated any provision of this agreement. User acknowledges that access to, and use of, the Consumer Data may also be or become subject to regulation under state or federal law or regulations, including but not limited to the Health

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Insurance Portability and Accountability Act of 1996 (HIPAA), and agrees to Use the Consumer Data in strict conformance with all such laws and regulations.

The covenants of this agreement shall survive expiration of any separate agreements between Commission and User, Commission and User's employer, or User and User's employer, as well as termination of this agreement for any reason.

I understand that I will receive a signed copy of this Agreement, and that the signed original will be placed in my personnel file.

I acknowledge responsibility to comply with this agreement:

Signed this _____ day of _____, 20__.

SIGNATURE: _____ Name (Print): _____
USER

TITLE: _____

RECEIVED BY: _____ Date: _____
User's Immediate Staff Supervisor

PROGRAM NAME:

ORGANIZATION:

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USER CONFIDENTIALITY AGREEMENT – For Commission Staff and Consultants

- All staff, consultants and members of the Children & Families Commission of Orange County (Commission) who are responsible for gathering, maintaining or accessing confidential information or confidential records must read and sign this Agreement.
- After this Agreement has been signed, the original Agreement must be sent to the Commissions' Privacy Officer who will sign the Agreement.
- Once signed, the Privacy Officer will file the original Agreement in the Commissions' personnel files, and return a copy to the other signatory.

The undersigned (User) has been authorized by the Children and Families Commission of Orange County to have electronic access via the Internet to a data base containing consumer data (Consumer Data) maintained by Database Vendor on a secure website. Some of the Consumer Data may be in a personally identifiable format. All Consumer Data, regardless of whether it is personally identifiable, is deemed to be sensitive, proprietary, and confidential. Unauthorized use or disclosure of Consumer Data could have serious adverse consequences for the Children & Families Commission of Orange County ("Commission"), Database Vendor, User, User's employer, and the consumer(s).

User hereby expressly agrees not to use, display, disclose or otherwise exploit (Use) the Consumer Data in any manner, directly or indirectly, for personal, commercial, or financial benefit of any kind, nor to permit such Use by any other person, except as may be necessary for User or User's employer to provide, or facilitate the provision of; medical services to the consumer(s) whose data is Used; and otherwise in strict compliance with any mandatory guidelines issued by Commission and Database Vendor from time to time regarding access to and Use of the Consumer Data, to which User hereby agrees to be bound.

User acknowledges that unauthorized Use of the Consumer Data could cause irreparable harm and damage to the consumer(s) and/or Commission, for which the consumer(s) and/or Commission may seek legal remedies. User shall indemnify and hold Commission, its officers, directors, employees, and agents, harmless from any and all costs, expenses, damages, or liability of any kind whatsoever arising from any Use of the Consumer Data by User, or permitted by User, in violation of this agreement.

The Consumer Data is the property of the Commission. Nothing herein shall be construed to grant to User or to User's employer, any ownership or access rights to the Consumer Data except as expressly set forth herein. Commission may terminate the access rights of User to the Consumer Data at any time if, in the sole judgment of the Commission Administration, termination of access is necessary or appropriate to preserve the confidentiality and integrity of the Consumer Data, regardless of whether User has violated any provision of this agreement. User acknowledges that access to, and use of, the Consumer Data may also be or become subject to regulation under state or federal law or regulations, including but not limited to the Health Insurance Portability and Accountability Act of 1996 (HIPAA), and agrees to Use the Consumer Data in strict conformance with all such laws and regulations.

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The covenants of this agreement shall survive expiration of any separate agreements between Commission and User, Commission and User's employer, or User and User's employer, as well as termination of this agreement for any reason.

I understand that I will receive a signed copy of this Agreement, and that the signed original will be placed in my personnel file.

I acknowledge responsibility to comply with this agreement:

Signed this _____ day of _____, 20____.

SIGNATURE: _____ Name (Print): _____
USER

TITLE: _____

RECEIVED BY: _____ Date: _____
Privacy Officer

PROGRAM NAME: CFCOC

ORGANIZATION: CFCOC

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Appendix 4

**Prohibition on Redisclosing Confidential Information Concerning
Consumers Receiving Services**

This notice accompanies a disclosure of confidential information concerning a consumer of services funded by the Children and Families Commission of Orange County. This information has been disclosed to you from records protected by State and Federal confidentiality rules, including, but not limited to, 45 CFR Part 46, 42 CFR Part 2, or 45 CFR Parts 160 and 164 (HIPAA Regs.) These confidentiality rules prohibit you from making any further disclosure of this confidential information unless further disclosure is expressly permitted by the written authorization to release the information of the person to whom it pertains or as otherwise permitted by these regulations. A general authorization for the release of medical or other confidential information is NOT sufficient for this purpose. The Federal rules specifically restrict any use of the information to criminally investigate or prosecute any alcohol or drug abuse by the consumer.

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Appendix 5

**MEMORANDUM OF UNDERSTANDING
FOR EVALUATOR/RESEARCHER ACCESS TO AND USE OF OCERS PROGRAM
DATA**

This MEMORANDUM OF UNDERSTANDING (“MOU”) between the Children and Families Commission of Orange County (“Commission”) or _____ (“Grantee”) and _____ (“Evaluator/Researcher”), shall be effective starting on _____ (date) and ending on _____ (date) with reference to the following:

Background:

The Children and Families Commission of Orange County (“Commission”) is a recipient of Proposition 10 (California Children and Families First Act of 1998) funds to be used to promote early childhood development from prenatal to age five. The Commission’s mission, as stated in its Strategic Plan, is to provide leadership, funding and support for programs that achieve its vision that all children be healthy and ready to succeed when they enter school. The Commission has contracted with a Database Vendor to implement an Outcomes Collection, Evaluation and Reporting Service (OCERS) to permit Commission Grantees to report the outcomes of the services they provide to children prenatal to age five and their families. The Commission’s intent is to make use of aggregate level reporting (i.e. non-consumer-specific data) of the outcomes of service delivery across Grantees to evaluate their investments and apply best practices learned. [Individual Grantees, charged with collecting consumer-specific information on behalf of the Commission, will be responsible] or [The Commission is responsible] for ensuring that authorization to release confidential information and confidentiality protocols are followed to protect confidential consumer information.

With this Memorandum of Understanding, the [Grantee/Commission] agrees to share the following consumer data with the Evaluator/Researcher:

Data to be shared (specify from the following):

- child and/or primary caregiver
- program or programs from which data will be shared (e.g. Bridges, State School Readiness, all Commission-funded programs, etc.)
- data elements to be shared (e.g. consumer demographics, initial outcomes, core data elements, service outcomes, specific questions from any of these questionnaires, etc.)
- time period over which data were collected (e.g., initial interview data from July 1, 2004 through June 30, 2005; and/or 6-month snapshot data from January 1, 2004 through June 30, 2004, etc.)

The purpose for which these data are being shared is the following: _____.

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The data provided by the Commission to Evaluator/Researcher may be used for analysis and reporting for this purpose until *enter date*. After this date, the Evaluator/Researcher agrees to stop using the data until another MOU with the Commission is signed permitting further use of the data.

The Evaluator/Researcher agrees to:

- Use reasonable care so that the reports, studies, summaries and/or analyses it prepares in support of the Commission project are accurate.
- Provide copies of written analyses and reports from the data to the Commission prior to their publication.
 - Use reasonable care not to corrupt or alter any of the raw data supplied by [Grantee/Commission];
 - Cooperate with [Grantee/Commission] in its efforts to comply with the requirements as set forth in the [Commission Agreement] or [Confidentiality and Data Sharing Protocol].

Confidentiality. Evaluator/Researcher shall at all times maintain the confidentiality of all OCERS data supplied to it by [Grantee/Commission], including, but without limitation, billings, claims, and any audio and/or video recordings, in accordance with all applicable California and Federal codes and regulations relating to confidentiality, privacy, and/or security standards of patient or consumer records and other health care or confidential information, as they now exist or may hereafter be enacted or be amended, including, but not limited to, the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and regulations promulgated (or which may be promulgated) thereunder.

Access to Data and Records. Evaluator/Researcher understands and agrees that it receives no ownership or property rights in the OCERS data, and that the same, together with any and all reports, studies, summaries and/or analyses utilizing OCERS shall at all times be available to [Grantee/Commission]. With the exception of data extracted for purposes of research, data extracted from OCERS and reports using OCERS are to be used to satisfy contracted deliverables only and are not to be used for any purpose outside of the scope of the Commission's purposes. While access to the raw data will be provided, no personally identifiable information will be provided.

Indemnification Each party agrees to indemnify and hold harmless the other party, its officers, agents, and employees from all liability, claims, losses, and demands, including defense costs, whether resulting from court action or otherwise, arising out of the acts or omissions of the indemnifying party, its officers, agents or employees, or on the condition of property used in the performance of this agreement.

A paper or electronic copy of this MOU will be shared with the Database Vendor to facilitate transfer of the data. In addition, a paper or electronic copy of this MOU must be [submitted to] or [maintained by] the Commission to maintain with the [Grantee] and/or [Evaluator/Researcher] file.

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Signatures are on a separate page.

[Grantee/Commission] Representative

Date: _____

Name (Print): _____

Evaluator Representative

Date: _____

Name (Print): _____