TO: California Department of Social Services
        California Office of Systems Integration

FROM: CWS-NS Stakeholder Workgroup
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Re: **Developing California's New Child Welfare Case Management System to Support Children and Youth Through Better Information and Data Exchange**

The following material is provided by California's CWS-NS Stakeholder Workgroup to support further policy, practice, and design planning for a case management system that interfaces with the full care team, including many outside of the child welfare agency.

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I. Introduction

Since 2014, a diverse group of child welfare stakeholders—made up of child welfare advocates, health providers, dependency attorneys, former foster youth, and others —has been developing policy, practice, and design recommendations to support the development of a Child Welfare Services New System (CWS-NS) that interfaces with external systems and users in a manner that improves services and outcomes for children and youth in foster care. This Stakeholder Workgroup provided earlier recommendations as to how such a system should function (See Appendix F) and the functional requirements to underpin such a system (See Appendix G). In 2015, California Department of Social Services (CDSS) announced its intentions to deploy what it calls "self-service" features like those called for by the Stakeholder Workgroup. To support this end result, the Stakeholder Workgroup has developed the following package of materials to supply a starting point for a collaborative agency/stakeholder design and development process to be conducted by CDSS.

II. Articulating the Goals of External Interfaces

California is planning to develop what it calls "self-service" features in its new CWS-NS, allowing for new, external users from outside the child welfare agency (such as health providers, foster parents, and youth themselves) and exchanging data with new outside systems (such as school and health data systems). The ultimate vision of these features is to improve the child welfare agency's ability to manage cases, work more effectively with the youth, and coordinate with the broader care team to improve outcomes for children and youth in foster care.

California's child welfare stakeholder community supports the development of the new system to achieve the following goals:

1. **Goal: Gather more complete, timely, and useful data to inform care and ease transitions between placement and changes in status.**

   To be achieved in the following manner:

   - Link CWS-NS with available systems to provide timely, child-specific data to the child's record.
   - Provide opportunities for new, appropriate external users to routinely add to a child's record.
   - Support research and data analysis to enhance program planning and the ability to meet service needs.

2. **Goal: Ensure that the wider care team has access to important, usable care-related information at the point of service, so that appropriate, effective services are delivered.**

   To be achieved in the following manner:

- Provide online role-based access to appropriate members of the full care team to view select records and information housed in the CWS-NS.

3. **Goal: Connect members of the care team in a manner that supports child welfare agency efforts to oversee and coordinate care and facilitate the Continuum of Care Reform (CCR) effort.**

   To be achieved in the following manner:

   - Provide streamlined means for care providers to communicate with one another via the CWS-NS.
   - Deploy collaborative care planning documents that can be shared by the CWS-NS among designated individuals.
   - Provide notices and reminders that help keep team members on task.

4. **Goal: Engage foster youth in their own care and success; help set them up for independence.**

   To be achieved in the following manner:

   - Provide a mobile-enabled, interactive Web-based portal for foster youth who have begun the independent living planning process.
   - Share youth-focused, youth-facing collaborative planning instruments with youth via the youth portal.
   - Integrate connections to trusted, outside electronic resources designed to support the youth.

5. **Goal: Support efforts to protect privacy.**

   To be achieved in the following manner:

   - Leverage available technology functionality to facilitate privacy protections and manage role-based access.
   - Use technology opportunities to help providers and caregivers understand data-sharing parameters.
   - Track case activity and generate an audit log.

III. Realizing the Full Value of the CWS-NS Opportunity: Stakeholder Recommendations

Stakeholders present the following vision for how the CWS-NS should achieve the goals laid out above:

Bring Better Data into the Child's Record

- The CWS-NS will link and exchange data with relevant state systems. It could also link to county systems, regional health information exchanges, Foster Focus, and other existing systems, which may have more timely data than state systems.
    - Example: CWS-NS will be linked to Medi-Cal claims data, in accordance with new federal CCWIS rules. Such data should be used to build a health history for children when they enter foster care, allowing important information to be made available to health providers via a portal at the child's initial visit.
- The CWS-NS will be designed to collect some additional data, beyond what is collected today, through new data fields.
    - Example: When public health nurses click "other" from the health or mental health condition drop-down menu, the New System should be designed to give them a text box to provide further information.
- It will make relevant forms available for online submission.
    - Example: When using the Health Care Provider Portal, mental health providers will be able to retrieve the JV220A form, with some information auto-populated, and complete/submit it online.
- New forms should be developed to serve this purpose, to be shared and updated via the CWS-NS.
    - Example: CDSS could develop questionnaires that seek information directly from youth, to inform their care as well as agency planning.
- The CWS-NS should provide a streamlined means for external users to submit missing details or corrections to the record.
    - Example: When a foster parent or youth reviews the Health and Education Passport (HEP) online and sees incorrect information, they should be able to seamlessly send a secure email to the social worker to alert her to the problem. They should be able to attach a document to the message, to provide further details. The social worker would then manage the correction process.

Make Data Available When and Where It is Needed

- The CWS-NS will provide direct portal access for priority external users, including: foster youth, non-congregate substitute caregivers, health providers, dependency attorneys, and CASA volunteers, among others.

- Example: A Health Care Provider Portal would connect a licensed health provider to essential health records and supporting documents while also helping them exchange forms and related information with the child welfare public health nurse.
  - Data from the CWS-NS should be presented to authorized external users in a manner that supports ease of use.
    - Example: Data can be organized to allow a user to view summary information through a well-structured electronic HEP that is tailored to the user. It should also allow authorized users to obtain more detailed data in tabs that are specific to their role (i.e., dentists would be able to obtain dental records).

Connect the Wider Care Team

- The CWS-NS should provide an opportunity for direct, secure communication among the health care team.
  - Example: External users should be able to use the system to find contact information and send secure messages to other members of the care team. The system could provide Direct addresses (secure, HIPAA compliant) for use by health providers.
  - Example for future development: The CWS-NS could link health providers to a collaborative communication platform, allowing for real-time bi-directional, secure communication about their patients.
- Collaborative documents should be shared amongst a care team.
  - Example: As part of the Continuum of Care Reform (CCR) process, teaming instruments are being developed in paper form today. In the future, such instruments should be shared by the CWS-NS, and used to promote care planning and follow-up, among the interdisciplinary care team and with youth themselves.
- The system should have the ability to report on measures that reflect needs, progress, and outcomes at the case level.
  - Example: A social worker will easily be able to review what services have been provided to a specific child (health, mental health, and other), dates of service, and what recommended services have not been received.
- The system should provide notices and alerts, to keep members of the care team on task and remind the appropriate party to conduct recommended follow-up.
  - Example: Where a public health nurse has received a form that requires review and potential follow-up before being put into the child's official record, the document could be placed in a "tickler file" while it awaits review, with reminders being sent to conduct follow-up.

Engage Youth Directly

- o The system should provide youth with critical records and information.
  - Example: Using the youth portal, youth should be able to view a tailored view of the HEP that helps them manage their care needs.
- o The CWS-NS should help youth communicate with service providers.
  - Example: The CWS-NS should provide youth with secure notice/alerts of upcoming key calendar dates, such as ILP meetings job training events, and court dates, among others.
- o It should connect youth to resources that help them help themselves.
  - Example: The youth portal could offer an embedded link to an electronic resource like iFoster or the California College Pathways website, taking the youth out of the CWS-NS into the outside site to access its offerings and connect with other available resources.
- o It should provide youth with an easy way to generate the documentation needed to access external benefits, while in care and after having exited care.
  - Example: The youth portal should allow youth to print a verification letter, using the format provided in ACIN 1-27-16, that shows the dates they were in foster care in order to access benefits such as priority registration at college and college campus support programs.

Protect Privacy

- The CWS-NS must have the ability to manage role-based access and provide information to a user that is appropriate to their specific role.
  - Example: Where mental health data enters the CWS-NS, the system must be able to tag that data, treat it differently from other data, and reflect whether any authorizations for sharing exist and/or whether there's a court order in place that allows the parent to access such data.
- It must provide different views for different categories of users.
  - Example: Just as today the HEP can be printed with some information suppressed, the electronic environment must have the same ability to expose only those portions of the HEP that are appropriate to a user. In fact, an extra tab for nursing notes could be added to the HEP that would never be presented to foster parents, but that could be made available to the health care team through the Health Care Provider Portal.
- The system should make it easier to collect consents and authorizations.
  - Example: Non-minor dependents must provide consent for a public health nurse to work on their case and keep information, like the HEP, up-to-date. The youth portal should provide a streamlined way to get this consent and to explain to youth why it is important to do so.

- The CWS-NS should make consents and authorizations available for review, as well as providing name and contact information for health care and education rights holders.
  - Example: A school official who uses the system should be able to easily identify and contact the education rights holder for the child. Where none has been entered, the system should help the official figure out which party is the correct rights holder (and, should not simply display "default" without further explanation).
- The system should track and display the provenance of data, where it supports understanding how such data should be treated and/or understood.
  - Example: The case manager's view of the CWS-NS should indicate the role of the party that inputs information through color coding, tabs, or other means.
- The system should maintain and display audit trails that reflect access, sharing, and content changes, among other details.
  - Example: When a health provider submits supplemental information to support a well-child visit, the document should be automatically date stamped, and a contact made to reflect what was submitted by that health provider on that date.

Use Data to Improve Planning and Services

- The system will have the ability to report on measures that reflect needs, progress, and outcomes, at the case, community, and state level.
  - Example: A county could run a report on the number of children in care who have parents with substance abuse problems (if a field were added to collect that data systematically). This report would allow the county to evaluate whether the services available to help such parents are adequate.
- The system should allow counties or the state to run reports that address uniquely defined parameters of their own selection.
  - Example: A county should be able to pull up a history of a single foster home, in order to determine whether there are specific challenges at the home that need to be addressed.

Maintain a Human Element

While providing direct electronic interfaces to external users is intended to improve access to robust information at the point of service and communication through the most streamlined, consistent process, the electronic system will not be the only means for accessing information, communicating across the care team, or providing information to the child welfare agency, nor will the electronic system control all aspects of the data management process.

Supporting Privacy Protection

Though the CWS-NS should be programmed to automate as much of the privacy protection process as possible, the process will also have to include human elements (and allow for human discretion) as well, to ensure appropriate treatment of information. For example, users of the system should be able to tag data and documents as sensitive at the point of service. Furthermore, public health nurses should be able to decide not to include certain data in the HEP because it is too sensitive (such as an STD diagnosis code) and/or to flag it for sensitive treatment.

Maintaining Data Quality

Where human involvement is important today, it should continue and be incorporated into the future workflow. For example, where a form or information is submitted that requires review by a public health nurse before it is accepted into the official record today, that review should still take place in the New System. The process should be eased, however, by reducing duplicate data entry, through auto data population—and, the system should thus emphasize receipt of structured data, rather than PDFs, whenever possible.

Furthermore, in order to make sure that the data maintained in the record is useful and high quality, and that record does not become cluttered and hard to use, protocols will be required that support a social worker and/or public health nurse in determining what data, documents, and other contacts should be archived—or even deleted—rather than being incorporated into the case record. Of course, this will only be possible if adequate staff are available to support this activity.

IV. External User/Data Matrix

Identifying: (1) potential external users; (2) what information each user group can contribute that would enhance child-centered care ("input data"); (3) the information/data set that would support their ability to perform their role ("receive/access data"); (4) relevant guardrails; and (5) contextual notes.

Foster Youth Portal

Through a mobile-enabled, user-friendly interactive, secure Web-based portal designed specifically for and tested by youth, foster youth would have an opportunity to engage directly with essential core information about themselves, participate in care planning, and manage important documents. It could also allow youth to easily communicate with their care team and connect with available resources. Portal access would begin as a minor youth enters the independent living process and would continue to support the youth as they establish themselves in adulthood. The portal would not be the only means by which a youth obtains information and documents to which they are entitled. Where the portal does not provide access (such as to younger children) or does not provide everything that a youth is entitled to receive, the young person would follow existing channels to get what they need. The portal will handle sensitive data differently from non-sensitive data and, where indicated, such data will be provided in a manner that is understandable and with support from an adult.

External Users	Input Data	Receive /Access Data	Guardrails	Notes
Youth	Foster youth should be able to provide direct input to support their care planning and to communicate with members of their care team/social worker.	Foster youth need access to key data and documents that support their developing independence, engage them in self-management, and meet legal requirements.	The independent living and AB 12 processes would be used to familiarize youth with tools and available resources as well as to provide adult support, as necessary, for understanding and handling sensitive information.	AB 403 and the CCR effort reaffirm the expectation that the agency collaborate with the child, youth, and family in the assessment and case planning process. This developing practice is an ideal opportunity to improve/create collaborative care planning documents that would be shared with the youth through the youth portal.

External Users	Input Data	Receive /Access Data	Guardrails	Notes
Children who have not yet begun independent living activities	• As relevant, youth-facing questionnaires, forms, and planning documents. • Communications with social worker (email, other).	In general, younger children would not receive data directly from system until they are participating in transition to independent living meetings (see below).	In general, younger children would receive information to which they are entitled from caregivers, social workers, lawyers, etc., as appropriate.	
Youth who have begun the independent living training process (age 14 in many counties, 16 in others)	Same as above.	• Health & Education Passport (HEP) (including contact info for health, mental health, and other providers) • TILP • Case plan • Needs and Services Plan • Any other documents intended for youth use/collaborative planning with youth. • Calendar of upcoming hearings, appointments, etc. • Verification of foster care status.	Sensitive information should be presented[*] to youth only when it is actively requested and adult support is provided as to content and use. Best practices would include professional support where sensitive information is being provided to the youth—and, with respect to health and mental health records. Those health/mental health records that a doctor or medical processional believes would be detrimental to the youth will not be provided.	This resource should be incorporated into independence training and planning. See workflow ideas in "How Electronic Record Systems Can Help Serve the Goals of AB 12" at: http://childrenspartnership.org/publications/959-supporting-california-counties-in-transitioning-foster-youth-to-independence The HEP could be tailored for presentation to the youth, to make it reflect their needs more directly and separate out data that requires special treatment.

[*] Sensitive information is not easy to define, since the task requires some discretion alongside some concrete legal parameters. It includes: mental health information, substance abuse treatment (of child and parent), birth history (where substance abuse involved), reason for entering care, minor consent services, educational information that is sensitive (such as failing a grade), as well as other items defined as sensitive by the youth themselves. The sensitive information in the HEP is usually mental health information, but the HEP can sometimes contain reproductive health medication/ hospitalization information. In the current HEP, a box can be checked to indicate that there is additional, sensitive information in the file – and, it's important that when the HEP becomes electronic, that information not be exposed in the eHEP.

External Users	Input Data	Receive /Access Data	Guardrails	Notes
Age 18+ in extended foster care	Same as above. • Consents and authorizations (pursuant to new status as a non-minor).	Same as above.	It is important not to place any barriers in the way of accessing their own information. As with younger youth, best practices would call for having the social worker and/or a mental health professional go over sensitive documents with the youth. Such support should be considered part of the services due to youth in extended foster care.	Youth are entitled to access their full file at 18, but such access to the whole file need not occur through the youth portal. Counties will need to develop their own procedures for such access.
At emancipation /termination of care	Same as above. (Example, non-minors who attend their emancipation hearing by telephone could review and submit the JV-365 online, if they so choose.)	Same as above plus any additional information/ documents required per W&I §391(e) and 607.3 (f). • Information about public benefits (per W&I 14005.28) and 391(e)(3).	This process should make as many of the required documents/ information available electronically as possible, via the portal, and the agency should support electronic capture/scanning of additional documents as needed during the ILP process.	These youth sometimes go in and out of care until age 21, but the system should retain their data/documents continuously. Youth should be able to access portal until *at least* age 26, and should be notified and be able to download/copy the record before access is terminated. Verification of foster youth status should be available indefinitely and should not be subject to any age limit. It should be available regardless of the age at which dependency was terminated (AB 592 (2015)).

Substitute Caregiver Portal
Caregivers who take care of a child/youth every day need basic information to take on that task successfully, to determine their needs, inform other service providers, and make sure that follow-up needs are met. The portal should support caregivers in these tasks, in a mobile-enabled, user-friendly format.

External Users	Input Data	Receive /Access Data	Guardrails	Notes
Non-Congregate Substitute Caregivers (Foster parents, kin caregivers, home-based family caregivers)	Forms, reports, communications with social worker (email, other).	• HEP. • School Health Forms. • Child's case plan, and action/care planning documents. • TILP • Contact information for health, mental health, and other service providers. • All the things required by law, see ACIN 1-05-14, Attachment A.	Caregiver access should be automatically terminated when the youth reaches age 18. Caregiver access must be terminated at change of placement.	Child & Family teaming documents developed as part of CCR may be appropriate to share with some "family" caregivers. Law establishes a core data set that is essential to perform caregiving role; it does provide some discretion. (W&I §§ 16010, 16010.4(e), 16010.5(a); MPP 31-405(r), (s), (t); ACIN 1-05-14)
Prospective Foster Parents	Submit forms/ application and supporting documents.	None.	Child welfare staff who approach the prospective foster parent will provide them any data/items as per current practice.	The law gives lots of discretion about what is disclosed to prospective foster parents. Such discretion will be easiest to handle w/o providing prospective foster parents with direct access online (W&I 16010(d)).
Group Homes and congregate care facilities	Administrative data; file required reports online.	• Administrative data. • Therapeutic staff will need to have access to: HEP; TILP; Needs & Services Plan; and Case Plan.	Non-therapeutic staff should only have access to administrative data for administrative purposes.	As therapeutic staff are put in place, per CCR, such trained staff are to be active care planning participants and will need data appropriate to that role. Some persons within such settings will have role based access, that reflects their professional role (e.g., a nurse).

Family Portal

Biological parents engage in ongoing communication with the child welfare agency, as part of the reunification process. Furthermore, they need access to certain key materials and data in order to be able to participate as in the Child & Family Team. Portal access should support their being engaged in reunification activities and maintaining a role in their child's care, as set out in law. In addition, when a child returns home, this portal could continue to be a resource for the family and support continuity of care.

External Users	Input Data	Receive /Access Data	Guardrails	Notes
Biological Parents (where reunification services have not been terminated)	• Collaborative planning documents and forms that are intended for bio parents to provide input.	• Their case plan and any other materials intended to support their participation in reunification. • Calendar of upcoming hearings, appointments, etc.	Courts should be able to modify access, where it is called for by the circumstances.	Bio parents are often the education rights holder.

Health Care Provider Portal

Health providers are authorized to share information amongst themselves and with the child welfare team for purposes of treatment and care coordination. The portal should support the health care team in these activities, providing a comprehensive and up-to-date health care record that follows the child through transitions in care. It should also support the health care team in protecting a child/youth's sensitive information in accordance with their rights and preferences. (See Health Care Provider Portal Use Case and Mental Health Data Use Case for more detail, see Appendix C and D.)

External Users	Input Data	Receive/Access Data	Guardrails	Notes
Licensed Primary Care and Mental Health Providers	• Forms • Supporting material (for forms) • Care and action plans • Treating Instruments and	• HEP • Name and contact information for health care consenter and prior health providers. • Consents and authorizations • Beyond HEP: - Placement history - Health history (child and birth parents)	Health providers need (and are allowed) to see some data that is not available to the foster parent, and thus is not in the HEP. Such data may	• DHCS is providing counties with Medi-Cal claims information regarding psychotropic medication and other data that could be incorporated into the record, pursuant to the Global Datasharing Agreement. • Claims data should provide historic health data to the CWS-NS when a child

	Summary Reports from evaluations, screenings, and assessments, transition plans • Email	- Trauma history - Mental health history (including summary of Rx JV220A history), diagnosis and Rx; - Treating Instruments and Summary Reports from evaluations, screenings and Functional Assessments - Care and action plans - Summary of care, and discharge summaries, as available.	be in CWS/CMS, or is held by other health providers.	enters care (as is done in Texas). As they get developed, CCR Assessment and teaming documents are likely to be appropriate for inclusion. This would include "those developed collaboratively with youth and families."
School-Based Health Care Providers	• Immunizations • Summary of Care provided • Email	• Immunizations • Care & Medical Action Plans • Medication list • Name/contact info for health care consenters and current health providers. • Name/contact info of child's social worker		CA Immunization Registry (CAIR) could facilitate access to the full immunization data set, for school nurses and/or child welfare team.
Dental Providers	• Forms • Supporting Materials • Email	• HEP • Dental Records (as available, beyond those in the HEP) • Prior dentist contact information		

Other Care Team Members

An array of service providers support a child or youth in foster care, and each of them need some basic information to do their job, to communicate with other members of the broader care team, and to provide information to the child welfare agency. A portal should support these tasks.

External Users	Input Data	Receive/Access Data	Guardrails	Notes
Non-Health Contracted Service Providers	• Community service providers should be able to provide reports directly to child welfare online, and submit relevant attachments and to update the care/action plan for which they are a part of the care team. • Email to social worker	• Care/action and/or case plan relevant to their role.		
Schools/Local Education Agencies (LEAs)	• IEP • Name/address of school. • Attendance, courses/credits, transcripts, GPA, disciplinary records, IEP, name of teacher, standardized test scores. • Email to social worker	• Information necessary to determine: current placement, current caregiver, education rights holder, and education liaison. • Name/contact information for social worker. • Prior schools attended.	The Attorney General is developing guidance about disclosure to LEAs. Such guidance will determine which party at the school would have access to this data. FERPA consent rules will be applied.	AB 490 directs the education team to work together to meet a foster child's educational needs. The IEP is in the Special Education Information System (SEIS). Schools have access as part of the Special Education Local Plan Area (SELPA). An IEP could be provided through direct linkage between SEIS and CWS-NS.

Legal

A number of adults are charged with promoting the best interests of the child and youth in foster care, as part of the legal system. In order to promote the child's best interests, they need information that helps them understand those interests. The portal should support that understanding.

External Users	Input Data	Receive/Access Data	Guardrails	Notes
Mandated Reporters	Submit written report form (SS 8572) online.	None	System will need to send copy of form to police and district attorney, as well.	There will always be a need for a telephone interview, but online system could allow for additional communication and follow-up beyond that.
Dependency Attorneys	• Signed release of information forms • JV-222 (Opposition to Psych. Rx application)	• HEP • Court documents • Placement information and history • Contact information for social worker and supervising social worker • School placement information • Contact info for service providers (current and past)	County counsel would need to be involved.	
CASA volunteers	• Email to social worker	• Court documents. • Further data and documents being made available to a CASA, as provided by court order.	Access is upon appointment and court order (W&I §105). CASA cannot see any data that is tagged as privileged. Parent/child consent not required–except for requirement to get informed consent from NMD). (W&I §107(b)).	Social worker would select what documents to make available to CASA to reflect the court order and would curate the process much as it does today, making such documents available electronically where feasible. CASA could be important source for identifying errors and filling in missing details.

Dependency Courts	• Forms and documents, alerts (upcoming dates)	• HEP and documents/reports intended for court review.	Social worker will select the information to be entered in a court report to make sure that no privileged information is presented to the court.	New CCWIS rules require interfaces to be developed between courts and new CCWIS systems.
Probation	• Forms or documents intended for exchange with child welfare team.	• Probation officers and PHNs serving probation youth will have electronic access to the information that they currently receive.	• Youth have a Constitutional right not to have incriminating information shared with probation and with the delinquency court, as well.	This exchange refers only to those probation youth in foster placements.

Other External Entities: Rights Holders: Education, Developmental Services, and Tribal Representatives
Many of these rights holders will be granted access to a Portal based on another role (such as CASA, bio parent, foster parent, dependency attorney). Where they are not, they could obtain information relevant to their role from the social worker. As the CWS-NS Self-Service system matures, it may be advisable to develop direct access that is tailored to some or all of these specific rights holders.

Multi-Disciplinary Teams (MDT)
These teams will include the child welfare social worker, who will have access to the CWS-NS. This diminishes the need for others on the MDT to have direct access to the system for the purpose of working with the team. Other members of the team may also have role-based access to the CWS-NS through their role (e.g., mental health providers would have access via the Health Care Provider Portal).

V. Guiding Privacy Principles

The CWS-NS Stakeholder Privacy Workgroup developed recommendations for CWS-NS policy, practice, design, and IT functionality regarding features designed to receive information from and share information with new, external users to protect privacy and confidentiality while allowing for appropriate data-sharing that supports the best interests and care of the child.

These include:

1. The system must support, and shall not inhibit, the appropriate sharing of information among the care team to support care coordination and effective service delivery.

- The CWS-NS should support the child welfare agency in sharing information as required by law, within the parameters of applicable law and guidance.

- Any interface between the CWS-NS and the court system developed in accordance with new federal Comprehensive Child Welfare Information System (CCWIS) rules must be done in a manner that ensures that privileged information stays privileged and does not inadvertently get into the court record.

2. The system must be able to segment data, and manage different selections of data to be presented to different end users, as appropriate to their role.

3. The system must allow sensitive data to be treated differently than other data.

- Information can be defined as sensitive by law or professional judgment. In either case, the system should allow such data to be tagged to trigger a set of authorization/access rules and treatment. Tagging should be automated, to the greatest degree possible, but it should also be possible for the social worker, health or mental health provider, or other party entering the information to tag an item as sensitive.
- Protection of sensitive information must be built into the technical architecture of the system from the beginning.[+]
- Treatment of sensitive data applies to the chain of related information, including service notes, billing, pharmacy, diagnosis, and other.

[+] Consumer Partnership for eHealth, "Protecting Health Information in the Context of Health Information Technology" (June 2010) accessed June 28, 2016, www.nationalpartnership.org/research-library/health-care/HIT/protecting-sensitive-health.pdf.

4. Data-sharing agreements that safeguard the information and its use must be in place between entities and/or individuals that are involved in data exchange.

5. Technical functionality and practices shall be leveraged to support and simplify privacy protection.

- The system must provide secure access to authorized users, as relevant to their role, offer ID management/access capability, and support secure transmission of data.
- The system must be programmed with adequate granularity to support appropriate sharing, and shall: use metadata for data segmentation; flag sensitive data; sort by data type/source/purpose; capture consent/permissions and embed those in record functionality; and enable simple addition/retraction of consent/permissions. This shall include the ability to tag and segment portions of the HEP to be treated as confidential for handling according to appropriate laws, such that sharing the HEP is not an "all or nothing" proposition, as it is today.
- The system must be able to provide a limited view of the record that corresponds to authorizations and tagging.
- The system and related business process must be able to handle the often-changing status of a case.
- The system must be able to store, display, and retrieve consents/authorizations.
- The system must track and enforce start and end dates for authorizations, releases, and orders.
- The system must provide notices and warnings to assist users in handling data appropriately.
- The system should utilize check-list, decision tree, and other organizing structures to ensure that appropriate information is only shared where correct steps are taken.
- The system must: support the tracking and displaying of data provenance, support the application of source system rules, and ensure that provenance metadata persists even after being exchanged.
- Electronic signatures that meet accepted standards should be accepted as written signatures on authorizations and other documents.
- The system must have audit capabilities. This includes auditing as to changes to or deletion of records as well as disclosures to external users/systems.[++]

[++] Center for Democracy and Technology, *Rights and Requirements: A Guide to Privacy and Security of Health Information in California* (Oakland: California HealthCare Foundation, 2013), 6, accessed June 28, 2016, http://www.chcf.org/publications/2013/10/rights-requirements-privacy-security.

6. The system must support foster youth in having access to and control over their own information, as required by law and as appropriate to address their concerns about sensitivity.

- Where a youth reaches the age of majority or is emancipated, he or she will have access to and the ability to authorize disclosure of his or her own data, except as otherwise specified by law.
- The system shall flag and request new authorizations, as needed, from youth upon the child turning 18.
- For minors, the system shall support their control of information sharing relating to minor consent services, consistent with legal requirements, as well as store and display consents/authorizations in a manner that supports health and mental health providers in understanding their preferences and, to the greatest degree possible, automating appropriate treatment of such data.[**]
- The system shall also support rights of confidentiality in areas not related to minor consent services, such as education services.

7. Youth access should be defined to support their need for information and their ability to handle knowing and managing that information, as reflects their age, status, and circumstances.

- Online access to select data will be provided for all youth at the moment they enter the transition to independent living process. Before that, time, children/youth would request access to information through non-electronic channels, as is done today.
- Sensitive information should not be shown in a youth-facing record as a default mode, but rather should be presented only after the youth selects to view such data.
- Working in collaboration with stakeholders, the Department should develop processes for providing training and other adult support prior to access to certain sensitive material, such as mental health data, in a manner that is supportive but does not create an undue barrier.
- Where a health or mental health professional has concerns about information being presented to a youth, they should have the opportunity to indicate such concerns when they enter the data and suggest guidelines for addressing that possibility in the future.

[**] Helen R. Pfister and Susan R. Ingargiola, *Privacy, Please: Health Consent Laws for Minors in the Information Age* (Oakland: California Health Care Foundation, 2013), accessed January 28, 2016, www.chcf.org/publications/2013/01/privacy-please.

VI. Guiding Principles for the Development of Portals

A stakeholder workgroup was formed to lay out the principles required to ensure engagement of "external users" and optimal usability in the design of the CWS-NS's self-service features. Effort is required to optimize the interface and design of these self-service features now and improve them over time. Careful attention to the needs of the distinct groups of users (e.g., foster youth, foster parents, health providers, and others) is necessary as they will each approach the system differently, and they will approach it differently than "internal" users (social workers and public health nurses). Utilization of the new system by external users will depend upon appropriate design.

Stakeholders believe the following principles should guide the portal development process:

1. **Health Literacy**
Language should be carefully crafted and tested for the target audience. Jargon should be translated into "patient friendly" language. The portal should utilize, where appropriate, tools that increase users' ability to understand information more fully, such as: integrating links to definitions of terms; using movies and illustrations; and using graphs to track trending data.

2. **Usability**
Much of the literature surrounding usability confirms that adoption and sustained use of technology are directly related to ease of navigation and the perceived usefulness of the available information. Usability language in the intake RFP was strong, and RFPs for future modules should do the same—especially the RFP for the case management module, which will include the bulk of self-service features. A commitment to and investment in usability on the front end will ensure adoption and continued use by external users.

3. **Ongoing Feedback**
The development process should employ continuous iterative improvement in response to user feedback, even after deployment. We recommend that CDSS/OSI include a mechanism for gathering ongoing user input and a process for making changes in response to that feedback—including from external users. This process must be developed in a manner that minimizes delay in making changes, and that is accountable to all users.

VII. Next Steps in the Design and Planning

As CDSS and OSI move forward with designing and planning the self-service system, they should work closely with stakeholders to:

- Identify key decision points that must be made as the system and its portals are being designed.
    - o Central to this set of decisions is the selection of external users and the data that they will provide to/receive from the system.
- For each key decision point, determine what would be the best approach.
    - o This work should consider existing legal and practice constraints, while at the same time recognizing this as an opportunity to change policy and practice where doing so is necessary to facilitate appropriate information sharing.
    - o The effort should focus on what will: result in the most functional workflow, support the full care team in delivering effective care, and reap the greatest benefits for children and youth.
- Determine what policies, practices, and forms require change and/or further development and clarification.
- Develop plans for:
    - o engaging stakeholders and users in developing user stories and participating in robust user testing;
    - o obtaining ongoing feedback from stakeholders, external users, and child welfare staff; and,
    - o ongoing iterative improvement and modification that incorporates such feedback.

How to Get Started:
1. Start with the HEP. Develop plans to support the HEP being populated by better data, provided to appropriate team members in a user-specific view, with appropriate protections applied. To ensure that the HEP is completed, with timely data, pre-population of data should be used to the greatest degree possible, rather than manual entry. The HEP is a core summary data set.
2. Figure out the additional core documents (such as the Case Plan, the TILP, and others) as well as key data that would make a difference to care and outcomes, that can be provided alongside the HEP to appropriate users, as relevant to their role. Emphasize the development of improved, bi-directional shared care planning documents and forms that support care coordination in this electronic environment. Map these against the rules and practices that govern use of such data, and determine where rules, law, and policy changes would be required to effectuate the vision.
3. Develop plans for the envisioned communications elements that can make this system achieve much more than a paper process.
4. Working with stakeholders, reflect the decisions made in #1-#3 in "User Stories" that describe in clear terms how the system should function.

The CWS-NS Stakeholder Workgroup looks forward to being involved in the next stages of work and applauds California for taking this innovative approach to developing a system that improves services and outcomes for children in its care. Stakeholders are committed to helping plan and deploy a self-service system that achieves the goals described in this report, one that truly advances care coordination and promotes self-sufficiency for children and youth in foster care.

For more information about California's New Child Welfare Case Management System or should you have any questions about this report, please contact Beth Morrow, Director of Health IT Initiatives at The Children's Partnership, at (718) 832-6061 or bmorrow@childrenspartnership.org.

Developing California's New Child Welfare Case Management System to Support Children and Youth Through Better Information and Data Exchange

<u>Appendices</u>

Stakeholders:

Deep Dive into Health Data:

Resources:

Appendix A: Organizations that have participated in the CWS-NS Stakeholder Workgroup over the past two years

Accessing Health Services for California's Children in Foster Care Task Force – Carol Brown
Advokids – Erin Hupp
American Academy of Pediatrics, Chapter 1 – Katy Carlsen
California Alliance of Children & Families – Doug Johnson and Lynn Thull
California CASA Association – Phil Ladew
California Coalition for Youth – Paul Curtis
California School-Based Health Alliance – Serena Clayton
California Youth Connection – Joy Anderson and Vanessa Hernandez
Children and Family Futures – Sid Gardner
Children Now – Susanna Kniffen
Children's Advocacy Institute – Melanie Delgado and Christina Riehl
Children's Law Center – Sue Abrams and Brenda Dabney
East Bay Children's Law Offices – Roger Chan
FosterEd – Casey Schutte and Deborah Stephenson
Health Care Program for Children in Foster Care – Craig Demers
John Burton Foundation – Amy Lemley and Debbie Raucher
National Center for Youth Law – Bill Grimm, Rebecca Gudeman, and Michael Place
Public Counsel – Martha Matthews
Social Change Partners LLC – Reed Connell
The Children's Partnership – Korey Capozza and Beth Morrow
United Ways of California – Judy Darnell
Youth Law Center – Alice Bussiere

<u>Public Health Nurses from the following counties</u>:
Alameda – Pat Dorais (ret.), Dena Proctor, and Lori Trigalett
Glenn – Jenifer Norris
Lake – Carolyn Holladay and Sherylin Taylor
Los Angeles – Julia Wood
Sacramento – Joan Aubin
San Diego – Anita Secor
San Francisco – Juliet Halverson, Anne Trevino, and Vonica Yee
Santa Cruz – Erma Coty (ret.) and Deborah Wright
Shasta – Brenda Parish, Margaret Quintana (ret.) and Nancy Shifflet
Solano – Roberta Bresler-Sullivan
Sonoma – Cathy Ishizu and Anne Nadler
Ventura – Veronica Ruiz

Note: These materials have been developed through a series of Workgroup meetings beginning in 2014, some meetings with just Public Health Nurses, and extensive monthly sub-Workgroup meetings beginning in 2016 to discuss specific details related to: selection of external users and data, protecting privacy, defining how the system will handle external data, and ensuring the most user-friendly results. For further information about the Workgroup, contact Beth Morrow, The Children's Partnership, at bmorrow@childrenspartnership.org or (718) 832-6061.

Appendix B: Ensuring that the CWS-NS Does Not Replicate CWS/CMS Design Flaws: Public Health Nurse Perspective

The CWS-NS Stakeholder Workgroup included active participation by Public Health Nurses (PHNs) (See Appendix A). What follows is their list of ways that the CWS-NS must improve upon the current Child Welfare Services/Case Management System (CWS/CMS).

1. **The New System must be able to handle two staff working on a case file at a time.**

Currently, when two staff work on a case file at the same time, only one of them will be able to save the information that they have put into the record. In fact, whoever saves their work first gets that data saved, and the other has all their data wiped out. This occurrence happens frequently (as between caseworkers, supportive staff, and PHNs), is very frustrating, and makes staff hesitant to put data into the system.

2. **The New System should have better designed drop down menus and text box space limitations should be removed, to allow for more accurate input of data.**

Currently, PHNs are unable to input accurate and complete data on many health-related matters due to the constraints of the drop down menus and space limitations in the text boxes. Specifically, they note that:

- Diagnoses/Conditions: PHNs are often required to list health and mental health conditions as "other," which provides very little information to health providers and caregivers. Where "other" is selected, a text box should pop up.
- Medical Test Type: The drop-down menu should be expanded, deleted, or changed to a write-in box.
- Psychiatric Diagnosis: The drop-down menu should be revised to match ICD diagnoses. The system should also include commonly prescribed psychotropic medications.
- Well Child Exams: Drop-down menus should be added for BMI and BMI%.
- Birth History: More space should be provided for the APGARS and in the write-in boxes. In addition, the following should be added to the drop down menu for positive toxicology under birth history: opiates, methadone, and amphetamines.
- Exam Refusal: A check box should be available to indicate when an exam is refused, and by which party (child, substitute care provider, relative).
- Schools: The New System should provide an up-to-date list of schools and the ability to input schools if they are not listed.
- Space limitations in text boxes can limit their effectiveness. This is particularly true of the Well Child Exam and medication boxes, which should have no space limitations.

3. **The New System should identify which party entered the information in the record.**

The current record does not identify which contacts were entered by the PHN and which were entered by the child's social worker. Such information would be very useful to staff, to help

them locate and organize data as well as to give it some context. As new, external users begin to submit data and documents for inclusion in the case record, this issue will become even more important.

4. The format/process for entering psychiatric medication dates should be changed.

The current requirement for a start and end date for psychotropic medications results in misleading information in the record. In fact, an end date may simply indicate the date that a child visits with a new doctor, rather than a change in medication. The New System should be able to capture the fact that a child/youth is "continuing the same medication" and other, more accurate, designations. One suggestion is to auto-calculate and populate the projected end date with 6 months/180 days from court order date and trigger review by the PHN at that date.

5. The New System should allow authorized staff to clean up a record.

Where errors are introduced into the record, it is currently a challenge to correct the record—even where a staff member is attempting to correct a known error that they entered themselves. PHNs believe it is important to develop a process that allows for such corrections, and recommend that:

- editing capability should be added, but be limited by restricting edit authority to the information that the staff member, themselves, entered (or, possibly to that entered by others in the same role assigned to the case); and
- edits and changes should be tracked. This could include retaining deleted and changed information in grey text.

6. The New System should capture health provider information in a new manner.

Today, PHNs find it challenging to identify the correct physician for a child because a provider search doesn't provide a view of the descriptive data (such as detailed address information) that can help differentiate between providers. In addition, PHNs indicate that the facility/clinic is more often relevant than the provider. PHNs suggest that the provider be indicated by their clinic, and then the narrative used to indicate a specific physician or provider.

7. The New System should modify the process for completing and populating the HEP.

Currently, when PHNs go into the orange block to record a well child exam, they must click "ok" for the information to be populated into the HEP. This becomes particularly problematic when dental information is being entered, because PHNs often do not enter the well child section when entering dental data, since they enter the dental data in another section. Furthermore, PHNs indicate that when printing a HEP, they are not given an option to "collect all information." This process is burdensome and can result in incomplete information in the HEP. PHNs suggest:

- the drop-down menu should trigger the population of the HEP; and
- the PHN should be able to select "collect all information" when creating, renewing, and printing the HEP, rather than being required to click every single section.

8. **The New System should capture annual physical and dental exams.**

   PHNs recommend that the record be organized to capture well physical and dental exams as annual events, not by periodicity (despite the fact that federal law addresses the requirement in terms of the periodicity schedule).

9. **The New System should automate PHN secondary assignment.**

   PHNs recommend that PHNs have automatic secondary privileges upon logging on, since PHNs carry the cases. Such a change would remove an administrative barrier to PHNs doing their job.

Appendix C: Health Care Provider Portal: Use Case

The Stakeholder Workgroup has developed the following vision for how the Health Care Provider Portal could facilitate access to appropriate, timely, health care-related information that informs care while also creating opportunities for care coordination and secure communication among members of the health care team.

The Problem
A foster patient is often a new patient for a pediatric health care provider. The only information available to that provider during the patient visit is the Health & Education Passport (HEP), which is provided by the substitute caregiver in a paper binder. Sometimes, the HEP is not even provided; and, when it is provided, it is rarely complete. Adding to this challenge, foster parents and children in foster care are unlikely to be able to verbally fill in the picture. Even where the child is a returning patient, data are usually limited.

Similarly, a child who is new to foster care usually does not have much if any health information in their child welfare record until they have the first health visit with a provider (30 day). However, their health needs start the day they enter care. Public health nurses working for the child welfare agency would like to have better health information at their fingertips from day one.

The HEP itself is problematic as the sole source of information for delivering health care. Even when fully complete, it does not contain all of the information required for pediatric health care providers to understand a child's needs. Some critical information that resides in the CWS/CMS is generally not included in the HEP, such as the child's trauma history and psychiatric diagnoses. Though the provider is able to get that information if they call the caseworker, it is generally not available at the time of service—and, challenging to obtain when they try. Furthermore, key health care documents that may be in the case file are not in the HEP (such as Discharge Summaries and dental records). Finally, the current CWS/CMS includes a very limited set of diagnosis codes that result in "other" being entered frequently, though that designation is of little value to the health care team.

County practices vary as to what happens after the foster patient visit—but, in general, the practices include many opportunities for missed connections and gaps in the record. Standard practice finds the health care provider completing a specified form and handing it to the foster parent, who is supposed to give it to the social worker. The provider may also give the guardian a summary health document from their internal electronic health record system, or other supplemental materials. In some counties, the health care provider is able to submit the form[s] and possibly some supplemental material directly to the child welfare agency, by fax, mail, telephone, or online. Once the county receives the information, the public health nurse then hand enters relevant data into the CWS/CMS, some of which will be displayed in the HEP. During that transfer of information, the nurse will identify errors or gaps in information that require a call to the provider, look for issues that require follow-up, and perform other case management functions. The nurse then transfers all paper records to the caseworker to be held in the paper case file.

<u>Proposed Solution</u>
The CWS-NS should offer a Health Care Provider Portal that enables licensed health providers (primary care, mental health, and dental providers included) to access health information about their foster patients, at the point of service, and to submit information electronically to the patient's child welfare team. To the greatest degree possible, the Portal should be capable of being integrated into the standard workflow of the provider's office.

For this proposed solution to provide adequate value, the HEP must become a more robust resource. Such an outcome is possible if the HEP is kept up-to-date with timely data that comes in from all relevant data sources and captured in a usable manner. However, it is also important that the Health Care Provider Portal not be limited to viewing the HEP.

This solution should build upon the legal authority of health care providers to share robust personal health information with other health providers, for purposes of treatment and care coordination, and should enable communication as between such providers.

<u>How It Would Work</u>
Enrollment
Licensed health care providers and their organizations would enroll before being able to use the Health Provider Portal. This enrollment process would include signing a Data Use Agreement, providing administrative/identifying/licensure information, and indicating their provider type/specialty. Role-based access to information about their patients will reflect their provider type and professional licensure.

Portal Access
Provider access would occur through a secure, Web-based platform that meets accepted security and usability standards. When an enrolled health provider logs in, he/she (or, their designee) would see their full panel of foster care patients—from which to select a particular patient—and would have the opportunity to add new patients.

Registering Foster Patients
For each new foster patient, the provider would submit basic identifying patient information to register them as part of their active foster patient roster. In turn, the provider information would be captured by the CWS-NS and associated with the patient.

A patient account should stay open for as long as the provider is identified as the child's provider in the CWS system. Where a new provider contact is entered into the CWS system, the earlier provider's account would be "end-dated" and the case moved into an inactive roster. Providers should be able to easily reactivate the case, if the child returns to their care.

Data Retrieval
When the health provider selects a registered active foster patient, the system would query the CWS-NS and pull up the select set of health and related information about the child that reflects the health provider type (role-based access). Ideally, the CWS-NS will be populated with select Medi-Cal claims data when the child enters into care, providing some health history from day one, for most children.

The information must be presented in a user-friendly, organized format, for view, print, and/or download depending on the type of data. Information that is tagged as sensitive would be presented in a separate tab, allowing only authorized providers to view that information, after entering an additional access code. Information that is not available for re-disclosure, without further authorization, will be tagged as such.

If a provider has an EHR that is interoperable with other record systems and/or an HIE, the provider would ideally be able to incorporate use of this Portal into their standard workflow and integrate the data as he/she does from other record systems and the HIE.

Primary health care providers have expressed the need for the following data:

- HEP
- Beyond the HEP
  - Additional health and mental health history details:
    - Placement history (date entered care, number and type of placements)
    - Health history (longitudinal)
    - Trauma history
    - Mental health history (summary of past JV220As and rulings; past and current diagnosis and prescriptions)
- Contacts for care team (including secure "direct" address[+] or other email address, as well as fax and phone):
  - Name/contact info for prior mental health provider(s)
  - Name/contact info for other service provider(s)/care team
  - Name/contact info for prior primary care provider
  - Name/contact info for child's case manager and assigned public health nurse
  - Name/contact info for health care consenter[*]
- Care planning documents, such as:
  - Treating instruments and summary reports from evaluations, screenings, and assessments
  - Care and action plans
  - CCR Assessment and Teaming documents
  - Summary of care and discharge summaries
- Consent information:
  - Health care consents and authorizations

[+] For more information: https://www.healthit.gov/sites/default/files/fhadirectedexchangeguidelines.pdf.

[*] It is important that the health care consenter/rights holder be provided, and kept up to date. Where there is none put in, the system should help the health provider understand who has consent authority—rather than just putting in the word "default" with no explanation.

Licensed mental health providers have expressed the need for the following:

- Same information as given primary health care providers (listed above)

Plus:

- History of juvenile justice involvement
- Length and intensity of psychiatric service history, and type of treatment.

Dentists should be able to view the following:

- HEP
- Dental records
- Prior dentist contact information

School Nurses/School-Based Health Care Providers should be able to view the following:

- Immunizations
- Care Plan/Action Plan
- Medication List
- Name/contact information of primary health care consenter
- Name/contact information for child's case manager and assigned public health nurse

Data Input
Using the Portal, health care providers should be able to:

- access, complete, and submit pre-populated required forms online and/or print such forms to complete by hand;
- submit attachments and supporting materials online, such as a provider's own wellness visit form or other standard summary of care and transition planning documents created by the health provider's EMR; and
- access and complete care coordination instruments, such as those being developed for CCR.

The health care provider should be able to tag such data/documents for special treatment (e.g., as sensitive, not for discussion with youth, and the like).

Following current practices, PHNs will review all data and documents before entering and/or accepting them into the child's CWS-NS case record—and, will follow up with health providers where necessary to complete/correct a document.

Data Sharing
To the degree possible, data-sharing rules should be programmed into the system. In addition, decision-making tools should be embedded in the system that help a health care provider understand a child's rights and appropriate treatment of their information, given the child's age, status, type of service, source of the data, and consents/authorizations. Decision-making tools should include flags, pop-up notices, warnings, and a decision-tree structure to follow

before sharing information that has been tagged as requiring special treatment. Such tools must be centered around the child's best interests.

Each provider would have the option of obtaining consents and authorizations as per their standard practice, for retention in their own records. Where a patient/health-care decision-maker wants to modify the consents/authorizations from those in the CWS-NS, the provider could capture the new consent/authorization, using the appropriate form that can be completed online, and submit it to the public health nurse to update the CWS-NS.

From within the Health Care Provider Portal the health provider should not be able to share any document/records except with child welfare staff (public health nurses and social workers), and with their patient/guardian. However, the provider would be able to enter/download information or documents into their own record, as allowable by law. Authorization would be required for the provider to re-disclose any such information/documents for any purpose other than treatment/care coordination.

Communication
The Health Care Provider Portal should allow the provider to send and receive a secure email to/from the child's social worker and/or public health nurse, with attachments. It should also provide them with the information (and links) needed to exchange secure messages with other health providers. In addition, the Portal should allow a health provider to send emails and reminder notifications to foster parents and older foster youth, with such contact being reflected in the case record. Recipients must be made aware of such communications through user-friendly procedures (such as email or text).

Consideration should be given to developing a shared notes feature for use only by health providers. The feature would allow for bi-directional communication, in real time, and would help providers track follow-up care. If necessary to address legal concerns, the platform might reside outside the CWS-NS, if that could be managed in a way that still fits with provider workflow. Public health nurses would be able to access the communication and, as appropriate, use it to update a child's record. Further exploration of this concept is needed, as it would greatly enhance care coordination and is sought by health providers.

Reminders
The system should generate a reminder for periodic wellness visits, based on the last visit, for the provider to send to the patient through the office's standard reminder procedures in accordance with foster care-specific periodicity guidelines. The system should also generate a reminder for recommended follow-up care, hopefully to accompany a shared care planning document, for a provider to send to the patient.

Tracking
Health data should be identified as to its provenance, as well as the date it was provided, in a manner that is visible to health care providers, since that information affects a provider's understanding of such data.

All case activity should be tracked and reflected in an audit log.

Other standard EHR functions, such as online appointment scheduling, providing educational materials, and the like will be provided through the health provider's standard system and procedures. For this reason, it is extremely important that the Portal fit into the provider's workflow and procedures, to the greatest degree possible, so that the EHR functions being satisfied by the Portal (such as reminders) are reflected.

Funding
Enhanced federal funding (90% matching rate) is available to support this work, per recent guidance which authorizes enhanced funds to electronically connect "eligible" health providers (i.e., those that have received federal funding to support meaningful use of electronic health records) with other Medicaid providers. Other Medicaid providers can include physicians who have not received such funding, public health nurses, and others. Some of the pediatric providers engaged through this Health Care Provider Portal will be eligible providers. The system will connect those eligible providers with "other" Medicaid providers and public health nurses. (Centers for Medicare & Medicaid Services, State Medicaid Director Letter, #16-003, dated February 29, 2016)

It is important to note that the role of public health nurses in the new, externally-facing CWS-NS environment will require adequate staffing to ensure that the system functions smoothly and that it supports real care coordination.

Appendix D: Mental Health Data: Use Case

This "Use Case" outlines a Stakeholder Workgroup proposal for how the CWS-NS can handle mental health information. Stakeholders feel strongly that some mental health information must be included in the child's health record. Without it, the care team is unable to serve a child's best interests. However, sharing of mental health information must be done carefully and the CWS-NS must handle such information differently from less sensitive information. Further, it is important to note that this area of practice is currently in flux, as guidance and practices are being developed to address new law (such as SB 238) and Continuum of Care Reform (CCR).

Background: In general, mental health providers in California are required to use electronic health records (via a county-run EHR system) when serving Medi-Cal patients. Ideally, these county-run EHR systems will be interoperable with the CWS-NS (or, an intermediary HIE or similar hub), and a provider would be able to integrate the CWS-NS Health Provider Portal into their workflow.

When a child in foster care gets mental health services, a diagnosis, and a prescription, what should happen to the mental health data/records?

The provider would use the CWS-NS Health Care Provider Portal to pull up their panel of foster care patients, select and retrieve a specific child's record, access the electronic JV220A and other structured forms, and direct the system to auto-populate the form(s) with some relevant data from the child's CWS-NS case file.

- Only a licensed provider should be able to view the sensitive information. Administrative staff would view only administrative details and non-sensitive health information as per standard EMR office practice.

From the Health Care Provider Portal, the licensed provider would be able to view:

- Health & Education Passport (HEP)
  - Including contact information and email (secure "Direct" address, if available[++]) for prior health and mental health providers.
- Name and contact info for health consenter
- Consents for services and authorizations for re-release of information
- Additional detail (beyond what is in the HEP) regarding:
  - Health history (child and birth parents)
  - Medication history
  - Trauma history
  - Placement history
  - Mental health history (including length and intensity of treatment)

[++] For more information on Direct addresses, see https://www.healthit.gov/sites/default/files/directbasics forprovidersqa_05092014.pdf.

- History of juvenile justice involvement
- Care Coordination materials, such as:
    - Treating Instruments and Summary Reports from evaluations, screenings and functional assessments, care and action plans, summary of care, and discharge summaries.

The provider would complete and submit the JV220A online, along with any supplemental records needed to justify a request for a Court Order for the prescription. A copy of the JV220A submission would be retained, and date stamped, in the health provider's file.

- Providers would have the option to print the form and complete it by hand, then submit it to the child welfare agency by fax or other means. However, the design of the CWS-NS/Health Care Provider Portal should drive the vast majority of health care providers to submit this document digitally.

The provider could also complete other care-related treating instruments and/or care plans and submit them to child welfare online, for review and inclusion in the CWS-NS as determined appropriate.

- Providers should have the ability to tag individual data items as sensitive (in addition to, or instead of, tagging a whole document), as should the public health nurse (PHN).
- As CCR assessment and teaming documents get developed, such documents would interface with the health and mental health providers via the Portal, and should be developed in a manner that promotes communication amongst the care team and engagement of the foster youth directly.

The JV220A will be transmitted to the court/mental health unit for review (this process differs across counties). Where there is a problem with the document/form, the unit will follow up with the provider to get the information fixed before sending it to the court for review.

When the JV220A has been approved by the court, it will be sent to the PHN for incorporation into the record and care planning. An alert will then be sent to the child welfare team to review the psychotropic medication authorization (PMA).

1) Relevant information from the JV220A would be auto-populated into the Health Education Passport (HEP), for review and acceptance by the PHN.
    a. Under current law, PHNs can enter data into the HEP that is then shared, per rules for the HEP. They can share information as necessary to coordinate care (W&I §5328.04). Clarification is needed to ensure that necessary mental health information is available to health providers to inform care and follow-up services.
2) The system should capture Medi-Cal claims-based health and mental health information in the child's record in a manner that allows PHNs to review and accept the data, using their discretion. Where such information is sensitive, the PHN should be able to tag it as such.
3) Where there is follow-up action required, the PHN should capture it into a Care Plan/Follow-Up Plan, to be shared with relevant members of the broader care team.

Electronic access to mental health data/records stored in the CWS-NS by authorized role-based users:

Youth:
Youth have the following rights that affect mental health information access:

- To know their diagnosis and treatment options, in language they can understand.
- To be involved in mental health decisions, treatment, and services.
- To tell a judge when they are opposed to psychotropic medication (JV-222).
- At age 12 and above, to see and get a copy of medical and mental health records, unless a health provider thinks it would be detrimental (H&S Code §123115).

Through the youth portal, youth in foster care (minors and non-minor dependents) would have routine access to a version of the Health & Education Passport tailored toward youth and to youth-facing shared care planning documents. The default HEP being shown through the youth portal could exclude sensitive information (such as trauma history.

To get sensitive information/documents (mental health and more) beyond the HEP, youth would request it from their social worker. The social worker would provide those that are appropriate (via electronic means or otherwise), and where support is required to handle any sensitive information, would arrange for that support to be provided.

Foster Parents/ Substitute Caregivers:
Child welfare agencies are required to share essential mental health information with caregivers. (ACIN 1-05-14) Via a portal, these caregivers would receive core mental health information through the HEP—which includes mental health history, known conditions, history, and medications, as well as mental health provider contact information. Additional mental health information that is given to the caregiver upon placement, such as known or suspected dangerous behavior on the part of the child, would be provided through other channels.

Health Care Providers:
Health care providers are able to share health-related information (including mental health) among themselves, and with county social workers and PHNs, for purposes of care coordination and treatment, without a signed authorization. (W&I §16010.2; 16501.3(c); Civ. Code §§ 56.10(c)(20), 56.103) Mental health information should be shared through the Health Care Provider Portal, in accordance with law and practice protocols. If necessary to address access concerns by mental health partners, the Portal could be developed to provide different access to mental health providers than to other health providers. However, care must be taken to ensure that primary health care providers have adequate information to support the child appropriately—especially as they are regularly tasked with managing a child's psychiatric medication, for which they need adequate supporting background information.

Appendix E: Health Care Provider Perspective: Survey of American Academy of Pediatrics, California Chapter 1

Methodology: Thirty-four pediatricians who participate in California Chapter 1 of the AAP completed the survey, which was sent to all Chapter members in April and May of 2016. The Chapter represents California pediatric health care providers working from the Oregon border to Tulare and Inyo counties. Participants answered 8 questions, most of which were structured to get open-ended responses. The open response format was chosen to ensure that the questionnaire did not suggest concerns and answers, but instead gathered their independent thinking. Participants were able to provide more than one answer.

Summary: The survey was introduced to Chapter members as an opportunity to educate CDSS on what pediatricians and other health care providers need in a new Foster Care Health Care Provider Portal. Despite the open-ended response format, the consistency of the pediatricians' responses was notable. Participants highlighted the need for accurate, timely, and reliable medical and mental health information about children in foster care at the point of contact to allow for better care coordination and effective treatment. Responses indicate that the current Health and Education Passport, currently the vehicle for informing a health care provider, is generally incomplete or not available to the provider at the time of the evaluation. A health care provider portal was viewed as a good solution to this problem, though participants indicate a preference for the portal to be integrated with the EHR systems they already use.

1. What information do you need to treat children in foster care that you don't get currently?

    - Mental and physical health history: 88%
    - Immunization records: 35%
    - Trauma history (reason for placement): 24%
    - Current medication list and medication history: 24%
    - Education information: 15%
    - Placement history: 12%
    - Problem list: 6%
    - Consent information: 3%

2. Do you have suggestions about how the missing information could best be obtained?

    - Secure, online repository of electronic records: 65%
    - Child welfare staff/Public health nurse: 15%
    - More readable medical passport: 9%
    - California Immunization Registry (CAIR): 6%
    - Prior providers: 6%

3. Would it be helpful to have prior health provider(s) contact information?

    - Yes: 94%
    - No: 0%
    - Not Sure: 6%

4. Would you contact those colleagues to get information?

- Yes—preferably by phone: 36%
- Yes—preferably by email: 48%
- Yes—other: 42% (of these, 30% specified that they prefer fax)
- No: 0%

5. What features would be most useful to you in a "Foster Care Health Care Provider Portal"?

Top answers provided:
- Access to health information: 83%
  - Many details provided about the type of information needed
- Contact information for caseworker: 10%
- Forms for completion: 10%
- Secure communication: 10%

6. If the Foster Care Health Care Provider Portal required you to go into a separate system from your own record system, would that be workable?

- 44% said yes with no caveats;
- 21% said yes, but that they would prefer if the Portal were integrated with major EHRs/HL7;
- 24% had some concerns that a separate Portal might be cumbersome.

7. Regarding the issues presented in (6), do you have any suggestions about how to make this work best?

Helpful suggestions included:
- Integrate with other EHRS: 65%
  - Some mentioned: Care Everywhere, P2P, CAIR
- Simplicity/ease of use would be more important than having lots of features: 9%
- Develop in a problem oriented format: 4%
- Standardize procedures across counties: 4%

(Note: Only 2/3 of respondents answered this question.)

8. What challenges or concerns do you anticipate about a Foster Care Health Care Provider Portal?

The main challenges and concerns raised included:
- Privacy: 26%
- Ease of use: 26%
- Quality of/completeness of the information in the system: 15%
- Duplication of current electronic systems (EHRs, CAIR): 12%
- Coordinating with other counties/states: 6%

Appendix F: Executive Summary of earlier Stakeholder Recommendations (submitted June 2014)

Excerpt from: CWS-NS Stakeholder Workgroup, *California Foster Care Advocate Input: CWS-NS Client-Level Outfacing Feature* (June 2014)

The Question

Should California develop an "outfacing" feature for its Child Welfare Services New System (CWS-NS) that allows a broader set of users to access case-level information? If so, what would this look like and how should it function to best improve care coordination for children and youth in foster care, while also protecting their privacy?

Summary

California's foster care advocates are very supportive of developing an "outfacing" feature in the CWS-NS. They see the potential value being multifold, including:

- Improving information that is available to health providers and other members of the care team, thus enabling better coordination and more effective care;

- Helping foster parents understand and meet the needs of children in their care;

- Easing the challenges posed by transitions in placement and status; and

- Empowering older foster and former foster youth.

Advocates urge that such an effort be crafted carefully to ensure adequate protection of foster children/youth's information. However, advocates were clear that it is possible to make CWS data available to a wider circle of users in a manner that appropriately protects foster children and youth's information. In fact, such sharing would promote the case management goals with which the CWS system was established.

Summary Recommendations

1. An outfacing feature (a "tool") should be made available as part of CWS-NS.

2. The tool should be made available as part of the state system, but in a manner that allows counties to customize it to local needs and connect with local data, which is often more timely and useful.

3. The tool should feed appropriate data directly to health providers, school counselors and foster youth services coordinators, dependency attorneys, substitute caregivers, and youth.

4. Data provided to courts should be actively selected and electronically transmitted by caseworkers rather than automatically, given the potential legal consequences of this information exchange.

5. The tool should support the inclusion of third-party data. If allowable under future federal law, such data should be incorporated into the CWS-NS with oversight and tagging as to provenance. However, if that option is not available under federal law, such data could be provided alongside CWS-NS data through the outfacing tool.

Examples of important third-party data that should be included in the care record include:

- Data from linked systems, like the California Immunization Registry (when it becomes bidirectional);

- Direct submission of health forms by health providers; and

- Contextual information/concerns shared by substitute caregivers with caseworkers and health providers.

6. The baseline information for outfacing would include what is required for the Health and Education Passport (HEP) (WIC §16010) and at emancipation (WIC §391(e)).

7. The tool should support emancipating youth in creating a repository of information and documents (per WIC§391, at a minimum) as part of the transition to independent living/exit process. Youth would control the tool at age 18 and be able to take their information and documents with them.

8. Key legal documents and authorizations should be made available through the tool, to appropriate parties, to facilitate the understanding of who has consent rights and what is allowed in terms of treatment at the point of service.

9. The tool should use the following electronic capabilities to enhance privacy protection:

- Role based/use limitations;

- Data segregation;

- Data tagging at point of service;

- Tagging as to the source of data/data provenance;

- Flags, notices, and prompts to help users understand how the data can be used and whether/how it can be shared;

- Access termination triggered as appropriate (e.g., at change in placement); and

- Trigger collection of updated authorizations (e.g., as youth age).

10. The tool must provide adequate security and an audit trail without becoming difficult to use.

11. The tool should enable submission of corrections by all users, which would then be reviewed and recorded, as appropriate, with tracking.

12. The tool could support robust exchange of health information among health providers for treatment and care coordination, without the complete health data set being exposed to others, as part of or alongside the CWS-NS data (per recommendation 5 above).

13. Mental health data should be included, with access controlled very carefully. Further exploration is required to determine what data, exactly, should be included beyond medication, treatment/follow-up instructions, and provider contact information.

14. Electronic functions could be used to limit available information to a first and second level of data, reflecting a user's role and/or showing a need for information. This multilevel approach could be applied to mental health, health history, and other complicated or sensitive data.

15. The tool/system cannot limit health providers to the options on a drop-down menu, because that would inhibit the providers' ability to provide accurate information.

16. The tool should support development of health, education, and life history, including, as possible, clinically relevant data directly input from systems such as Medi-Cal claims data.

17. The tool should facilitate communication and team planning among the care team, and between providers and youth, in support of *Katie A* implementation and AB12 processes, among others.

18. A paper version of the HEP must remain available for those that do not have access/facility with computers, and a back-up hard copy of original health records should be maintained by the caseworker. However, where a foster parent opts to use paper, electronic coordination and record development could still occur among providers and caseworkers.

19. This new system should be leveraged to allow for better data capture and analysis, including:

    - Gathering information about foster care placements to allow greater oversight of substitute caregivers; and

    - Capturing richer information about the reasons why children enter the system (including parental mental health and substance abuse problems) in order to allow for: better allocation of resources; improved prevention; and, enhanced ability to meet the needs of children who return home.

20. The new CWS-NS should be built in a manner that allows modification over time in order to keep pace with program changes and accommodate additional populations who intersect with the child welfare system (such as homeless minors).

Appendix G: Key Functional Requirements: Earlier Stakeholder Memo (copy)

TO: Kevin Gaines, California Department of Social Services
FROM: Beth Morrow, The Children's Partnership
DATE: Sept. 29, 2014
Re: Key Functional Requirements for CWS-NS to Enable Self-Service Options Going
        Forward

MEMORANDUM

The following list of high-level functional requirements is not comprehensive as to all CWS-NS functions, but is being provided to support the design of the CWS-NS in a manner that would provide adequate flexibility to position it, now or in the future, to interface with a broader set of users regarding case-level data as discussed in the Advocates' Report and Convening of July 29, 2014.

In fact, the following high-level functional characteristics would support the development of a modern, flexible case management system, while also providing it with outfacing potential, and we recommend that CDSS include these requirements in the RFP for the CWS-NS being issued in 2015:

1) Ability to interface and exchange data with external databases, Legacy systems, and information exchange environments at the federal, state, and county level.

[Example: CWS-NS should allow for the interface with California Immunization Registry (CAIR) and other chosen systems.]

2) Meets interoperability standards as identified by the California Systems Interoperability and Integration Project.

[Example: CWS-NS should meet NIEM, NHSIA, MITA, and other sharing standards.]

3) Ability to provide structured data to county-level systems and presentation layers that are configured to be interoperable with the CWS-NS.

[Example: CWS-NS should be able to provide consumable data to a county-level resource like Ventura County Foster Health Link.]

4) Ability to push and pull data in exchange with linked systems.

[Example: CWS-NS should allow a caseworker to query linked systems to get updated data on a child (such as immunization records from CAIR), and should allow a caseworker to push information out (such as a new address) to the source system, as appropriate.]

5) Ability to segment data to provide different presentations that reflect different end-users.

[Example: CWS-NS should be able to select and expose just the data that is to be made available to probation staff.]

6) Ability to manage role based access.

[Example: CWS-NS should be able to identify the specific role of each user (e.g., eligibility staff, public health nurses, foster parent, etc.) and allow them to view appropriate data and perform those functions that are authorized for their role (e.g., read, write, edit, etc.).]

7) Ability to store and display consents.

[Example: CWS-NS should retain and make available, as appropriate, documents establishing who is the education rights holder, among others.]

8) Ability to track case activity and generate an audit log.

[Example: The CWS-NS should maintain and display audit trails that reflect access, sharing, and content changes, among other details.]

9) Ability to track and display the provenance of data.

[Example: The CWS-NS should identify the role of the party inputting information (such as public health nurse, or foster parent) through color coding, tabs, or other means.]

10) Ability to send and receive secure messages, notices, and alerts.

[Example: The CWS-NS should provide end-users with secure notices/alerts of upcoming key calendar dates that require their involvement such as court dates and well-child visits.]

11) Ability to provide a report on measures that reflect needs, progress, and outcomes, at the case, community, and state level.

[Example: The CWS-NS should allow counties to request information that informs planning and service delivery, such as identifying cases that involve drug- and alcohol-problems among birth parents.]

It is of particular note that many California counties are engaged in innovative efforts to improve information exchange for this vulnerable population, and have developed (or, are developing) county-level systems and presentation layers that meet their needs. Importantly, these systems may contain county-level data that is more timely and relevant to care than the state-level data that will be made available through CWS-NS. Thus, we would urge the State to develop the CWS-NS in a manner that supports such county-level efforts, to the degree allowable under state and federal law. Many of the high-level requirements listed above would work toward that end, as would some of the deeper dive

requirements that follow. We would urge CDSS to gather input from relevant counties (such as Ventura, San Diego, Alameda, and others) with an eye towards this issue.

As the CWS-NS is developed to interface with a wider set of users, some additional, deeper dive, requirements would be recommended. Whether this outfacing feature takes the form of an electronic portal that is available to older foster youth or an electronic Health & Education Passport (HEP) that is available to substitute caregivers and provided, as appropriate, to health providers and other members of a care team, the following additional functional requirements would be recommended (alongside the high-level requirements addressed above):

Web based application providing secure anywhere/anytime remote access to authorized users.	Ability to provide an electronic graphical view of data, such as immunization records and growth charts.
Graphical User Interface front-end application that is user friendly, in plain language, and easy to navigate.	Ability to capture, store, and manage documents in multiple formats (e.g., PDF, jpg, etc.)
Supports secure communication between authorized users.	Compatible with portable devices such as tablets and smart phones.
Ability to automate and transmit notices, alerts, and reminders.	Provides search capability on all information and documents.
Ability for authorized users to electronically view and send selected data.	Ability to link to external websites and electronic resources through the portal.
Ability to limit sending data and reports to specific user profiles.	Ability to provide user with access to key documents and forms, for print, download, and/or online completion.
Ability to display data from multiple disparate databases and systems in an integrated format.	Alert users when certain documentation is required (e.g., a new authorization) and any limitations on redistribution.
Ability to display data as discreet data and images.	Ability to create and display a Health and Education Passport (HEP).
Ability to reference/store scanned images and documents and attach directly to case records as part of integrated workflow.	Allows user to create and display a task list.
Ability to segregate data to expose different views to different users, as according to their role.	Allows for updates and corrections by authorized users.
Multiple options for displaying list of case files (i.e., full family/caseload)	Supports audit logging of events per user, down to the field level.
Single sign-on capabilities.	Identifies and flags likely errors in data.

Appendix H: Additional Resources: Portal Planning and Design

Understanding the Data and Systems Needs of Pediatric Providers

Council on Foster Care, Adoption, and Kinship Care Committee on Adolescence, and Council on Early Childhood, "Health Care Issues for Children and Adolescents in Foster Care and Kinship Care," *Pediatrics* (2015), http://pediatrics.aappublications.org/content/136/4/e1131; Moira A. Szilagyi et al., "Health Care Issues for Children and Adolescents in Foster Care and Kinship Care," *Pediatrics* 136(4) (2015), http://pediatrics.aap publications.org/content/136/4/e1142.

Council on Clinical Information Technology, "Health Information Technology and the Medical Home," *Pediatrics* 127(5) (2011): 978-82, pediatrics.aappublications.org/content/127/5/978.

Council on Foster Care, Adoption, and Kinship Care and Committee on Early Childhood, "Health Care of Youth Aging Out of Foster Care," *Pediatrics* 130 (6)(2012): 1170-3, pediatrics.aappublications.org/content/130/6/1170.

Committee on Early Childhood, Adoption and Dependent Care, "Developmental Issues for Young Children in Foster Care," *Pediatrics* 106 (5) (2000): 1145-50, pediatrics.aappublications.org/content/106/5/1145.

American Academy of Pediatrics, "Health Oversight and Coordination Plans: Recommendations and Resources," https://www.aap.org/en-us/advocacy-and-policy/state-advocacy/Documents/HOCPs-AAP-Resources-and-Recommendations.pdf.

Usability and Consumer Engagement

Taya Irizarry, Annette DeVito Dabbs, and Christine R. Curran, "Patient Portals and Patient Engagement: A State of the Science Review," *Journal of Medical Internet Research* 17(6) (2015): e148, http://www.jmir.org/2015/6/e148.

Little Hoover Commission, *A Consumer-Centric Upgrade for California Government* (Report #229, October 2015), http://www.lhc.ca.gov/studies/229/Report229.pdf.

The Children's Partnership, *Engaging Foster Youth and Foster Parents in Electronic Records Initiatives: Lessons Learned* (May 2016), http://www.childrenspartnership.org/storage/documents/OurWork/ECC_White_Paper_2016_Final.pdf.

Consumer Partnership for eHealth, *Care Plans 2.0: Consumer Principles for Health and Care Planning in an Electronic Environment* (November 2013), http://www.nationalpartnership.org/research-library/health-care/HIT/consumer principles-for-1.pdf.

Agency for Healthcare Research and Quality, *Designing Consumer Health IT: A Guide for Developers and Systems Designers* (September 2012), https://healthit.ahrq.gov/sites/default/files/docs/page/designing-consumer-health-it-a-guide-for-developers-and-systems-designers.pdf.

Alex Baker et al., "Making the Comprehensive Shared Care Plan a Reality," *NEJM Catalyst*, May 18, 2016, http://catalyst.nejm.org/making-the-comprehensive-shared-care plan-a-reality.