## CALIFORNIA FOSTER CARE ADVOCATE INPUT

# **CWS-NS Client-Level Outfacing Feature**

Gathered and Compiled by The Children's Partnership

Through a Series of Convenings and Interviews In April and May 2014



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#### **Executive Summary**

#### 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, it should be incorporated into the CWS-NS with oversight and tagging as to data 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).

#### **Background**

In response to conversations with California Department of Social Services (CDSS) and California Welfare Directors' Association (CWDA), The Children's Partnership (TCP) was asked to convene California's foster care advocates to feed their input into the stakeholder process that is part of planning for the CWS-NS. This work follows directly out of the ongoing State Interagency Workgroup convened by TCP to discuss coordination of state agency activities that impact electronic information exchange of information for children and youth in foster care. An invitation to participate in the process was sent to all members of the California State Foster Care Task Force, Children's Advocates Roundtable, and the CDSS Advocates Meeting, among others. Participants are listed in Appendix A.

CDSS asked TCP to focus on what advocates envision for the potential outfacing feature of the CWS-NS, the results of which conversations are presented in this report. In addition, CDSS asked TCP to use these conversations to solicit recommendations for priority fixes to the current system (CWS/CMS) to ensure that it supports the work of child welfare agencies while the CWS-NS is being developed. This input is provided in Appendix C and further work will be done to gather these ideas.

#### I. Tremendous Value Identified

Advocate stakeholders uniformly feel that connecting data and caregivers is in the interests of children and youth in foster care, and that it is possible to promote child-centered care while improving well-being and health outcomes through secure, appropriate electronic exchange of CWS data with a wider circle of care partners, especially where the CWS system contains more complete information due to being fed by other relevant state and county data systems.

#### II. Outfacing How?

A tool that provides client-level CWS data to a wider set of users could take a variety of forms.

#### **Portal**

Data could be made available through a secure, online electronic portal that would allow designated users to access and update needed information, as appropriate, in real time, from all linked systems. A portal could:

- Be specific to a set of users (such as health providers, who are allowed to share robust health information amongst one another for treatment and care coordination purposes, as being pursued in the Institute for Population Health Improvement's Health Information Home/Project Inspire);
- Be specific to a set of data (such as psychopharmaceutical medication management, which involves greater privacy concerns, as is being proposed for the Office of Systems Integration Proof of Concept); and/or
- Be broadly applicable to the full care team, with access/view dependent on user role.

In addition to providing a view of data in the CWS-NS, a portal could:

- Serve as an online "gathering" site for inter/multidisciplinary teams, allowing for communication and joint creation of care plans, while also providing access to data that is differentiated by role. (Example: online education case management system called Goalbook, being tested in Santa Cruz County)
- Allow submission of data into the CWS-NS (or a parallel system) for appropriate view through the portal. (Example: Web-based, curated disease reporting and surveillance system, called California Reportable Disease Information Exchange or CalREDIE)

#### **Integrated Personal Health and Education Record**

Data could be made available to the full care team through a linked real-time record (accessible through a portal) that allows some users (such as foster youth) to create a repository to store and share information/documents that are not available in real time, and that serves as an electronic, enhanced Health and Education Passport or "electronic backpack." (Example: Ventura County Foster Health Link, being developed in Ventura County)

#### III. Outfacing to Whom?

Stakeholders uniformly identified great value in sharing tailored, appropriate information from CWS-NS with the following individuals outside the child welfare agency.

- Youth. Foster youth could be greatly empowered by having access to a more complete set of information/records and gaining some control over sharing that data. Other youth with information in the system might also benefit, such as runaway and homeless youth. Such a portal/record could function as an "electronic backpack" for these young people, like is being done by HealthShack.
- Substitute Caregivers. Foster parents and other substitute caregivers are challenged in
  providing appropriate care when they do not have adequate information and background
  to understand a child/youth's health, mental health, educational and social needs, and
  history. As such, relevant, timely data from CWS-NS could help them provide better care.

- Health Providers. Health providers serve children in foster care without having sufficient
  (or, often, any) information about the child's health history. They are also challenged by
  not having contact information for the current child welfare caseworker, to help
  coordinate care, among other contextual/coordination information. Further, they must
  rely on substitute caregivers to bring the HEP and forms for completion (like the PM 160),
  as well as to deliver the forms to the caseworker to be put into the CWS/CMS.
- School Counselors and Foster Youth Services Program Coordinators. Schools are unable to deliver appropriate educational services and support educational stability and success in the absence of information about the child's past school experience, relevant testing and educational plans, and other support needs.
- Multidisciplinary Teams. Multidisciplinary teams are an important part of the effort to
  improve care and are promoted as part of the Katie A implementation. Improving their
  ability to communicate, develop care plans, and share information through an electronic
  tool provides a great opportunity.
- Advocates for the Child/Youth. Dependency attorneys, education rights holders, and
  others tasked with representing the needs of the child often lack critical information to
  assist the child effectively, including information that is held by the CWS.
- **Courts**. In order to make the most appropriate rulings and guide caregivers in supporting the child/youth, judges need complete, timely information, some of which could be made available from the CWS-NS.

#### IV. Outfacing re. What Data

Advocates uniformly agreed that access to data must be carefully controlled in order to allow specified information to be provided to specified users, based on their role and the permissions given, as governed by the rules of the source system. Data that should be available, to be shared when appropriate, can be drawn from the siloed systems administered by the entities identified above (health, schools, and courts). Linking these and other relevant data sources through the CWS-NS could support communication and information sharing between important members of a care team. In addition, information provided to the system directly by users can become part of the exchange, as appropriate.

As a starting point, advocates believe that caregivers should be granted access to information electronically that they are already entitled to receive, as authorized by Welfare & Institutions Code (WIC) §16010, and older foster youth and nonminor dependents should be granted electronic access to the records and information listed in WIC §391(e).

Other data identified as being of particularly strong value includes:

- **Immunizations**. A complete immunization record could help prevent the common occurrence of duplicate and/or incomplete immunization of these children.
- **Legal Documents**. Imported, endorsed copies of Health and Education Minute Orders and the JV 220, among other key documents, could ensure care is obtained.
- Mental Health Data. Due to complicated rules and confusion, mental health data is often
  incomplete and inadequate to support ideal care. School counselors, physicians, foster
  parents, and caseworkers all need some information about mental health, with different
  information needed to perform each role fully.

- Attendance and Other Timely Education Data. Foster parents and caseworkers can respond to problems only when they have timely data, and such timely data could be provided by schools.
- Caregiver Observations and Concerns. Health providers and others expressed the opinion that they could provide better care if they had contextual comments from foster parents, such as "Johnny is unable to sleep at night," as well as from teachers and other health providers.
- **Health History**. At intake, very little health history is obtained for most children. Better collection of data at that point, and through linked sources such as Medi-Cal claims data, could improve care.

As part of the CWS-NS, this portal or electronic record would be made available at the state level as a feature of the state system that is available for counties to use. As such, it could reflect only data that is available at the state level, through the CWS-NS, or it could be customized at the county level and be able to show a view of both state- and county-level data, resources, and services.

#### V. Data Sources

Advocates feel strongly that it is important to connect across the systems that serve the foster care population, in order to improve continuity of care, support greater coordination, and make important information available at pivotal moments of care and transition. The data could also be of great value for research that supports program planning, resource allocation, and policy development.

However, while there was consensus among advocates that the following data sources could feed important data *into* CWS-NS (if allowable under federal rules), there was some concern that any data that flows *out* to these agencies be carefully selected to promote the best interests of the child.

#### **State-Level Data Sources**

In addition to those already being included pursuant to federal law (i.e., TANF, Medi-Cal eligibility, child support, and IV-B), advocates urge developing bidirectional interfaces with the following sectors that are involved in the lives of children in foster care.

- Probation: Juvenile Court and Probation Statistical System (JCPSS)
- Courts: California Case Management System (CCMS) (or replacement system)
- Mental Health: Short-Doyle/Medi-Cal (SDMC) System
- **Developmental Services**: Client Development Evaluation Report System (CDER) and Early Start Report System (ESR)
- Health Care: California Children's Services' (CCS) Children's Medical Services (CMS)
   Net, Medi-Cal Claims data in the Medicaid Management Information System (MMIS)
- Public Health: California Immunization Registry (CAIR) (or future 2.0 version), California Reportable Disease Information Exchange (CaIREDIE), and Automated Vital Statistics System (AVSS)
- Drug and Alcohol Treatment: Treatment Episode Data Set (TEDS) (federal) and California Outcomes Management System (CalOMS)

 Education: California Basic Educational Data System (CBEDS), California Longitudinal Pupil Achievement System (CalPADS), California School Information Services (CSIS), California Special Education Management Information System (CASEMIS)

#### **County-Level Data Sources**

To ensure robust, timely data, county-level data sources will also be critical. And, while each county is different and has different technology infrastructure at its disposal, the need to leverage county-level data remains paramount to caregivers and providers and locally identified care teams. Thus, the outfacing feature of the CWS-NS should allow for such interfaces and the population of local data, as appropriate, at county option. Of particular importance are:

- School District Data Systems. For instance, notification about school absences is timesensitive and vitally important for child welfare staff and substitute caregivers. However, such data will be most quickly available at the local level, and a time lag will be experienced in getting the data into CalPADS.
- Regional HIEs, Where They Exist. These could feed timely, complete health data into the CWS-NS directly or it could be presented through the portal/record to users in real time, alongside CWS-NS data.

#### **Third-Party Input**

Advocates agree that third-party input is extremely valuable and could help transform available records into a more valuable, timely, complete data set that portrays the whole child. Thus, if federal law clarifies that if such third-party data can be incorporated into the CWS-NS or, in the alternative, if it can be exposed to users through the same portal/record without entering CWS-NS, it should be done. In either case, such input must be handled carefully, in terms of entry, tagging, and sharing. In fact, public health nurses (PHNs) identified CalREDIE as a good model. There, third party input is entered into the system only after being validated by a social worker, which allows health providers to trust the quality of the record.

Third-party input can add value in a number of ways, including the following.

- Standardization. Health providers express concern about the current absence of a simple, standardized means for obtaining health forms and providing them directly to the caseworker. Under the best of circumstances, it can take weeks to get a form from the doctor entered into the CWS system. Instead, health providers would like to be able to access, complete, and submit such forms online. Such instantaneous communication of information could help a caseworker keep track of needed follow-up care in a more timely fashion, among other benefits.
- Context. Providers express the desire to learn more about the context in which a
  child/youth lives—a context that can only come from caregivers and the child's other
  support systems. Such input could be obtained for limited sharing with professionals
  from these wider caregivers through electronic questionnaires, uploaded records,
  comment boxes (allowing for free text), and electronic communication that is supported
  by the tool.
- Corrections. Outfacing technology opens up an opportunity to improve the data in the system. In the case of children and youth in foster care, erroneous data in the system can have devastating results. Public-facing CWS-NS records provide an opportunity for users to identify and submit changes to improve a child/youth's record.

#### VI. Research and Analytics

Advocates strongly favored developing the CWS-NS to enable a richer set of data to be available for research and program planning by internal child welfare staff as well as outside researchers. This issue is being addressed separately, with input from UC Berkeley Child Welfare Indicators Project and Chapin Hall, among others. At the same time, caution was raised against having analytics drive the development and design of the record, rather than the design being driven by what is needed to provide care.

Some ideas were raised, however, that are important to mention include:

- 1. The CWS-NS should be designed to allow child welfare agencies to track and evaluate data pertaining to caregiver and placements, in addition to tracking data about children and youth themselves. In that way, agencies could identify problems, get a better picture of what works and what doesn't in a placement, and develop strategies that improve placements.
- 2. Collecting and aggregating better information about precursors to child welfare placement, such as history of substance abuse and mental health problems among birth parents, could support the State in better allocating resources and delivering services with the goal of preventing children from entering care. At the same time, such data at an individual case level would enable child welfare agencies to better meet the needs of children who return to these homes.

#### VII. Concerns

Advocates reaffirm the need to gather and make case level CWS-NS information available carefully, while also expressing a belief that it is possible to do so. Some specific concerns, and related solutions, that arose in these meetings include the following.

#### Privacy/Confidentiality

Privacy is particularly important for children and youth in foster care. This concern exists today, in a paper environment, but electronic exchange of information presents some unique issues that must be addressed to ensure privacy of electronic information. Advocates noted, however, that an electronic environment provides new opportunities that can *help* protect data, such as flags where data is sensitive, and prompts that notify caregivers how to treat the data. For instance, the tool could identify that the data is for treatment purposes and not to be shared, or it could prompt the provider to release confidential information only when a court order is in place or under certain exceptions. Such features should be utilized for any CWS-NS outfacing tool.

Some discussion was held about the following:

- Sharing has implications going beyond the individual child/youth, since there are siblings and other family members who must be considered and may be negatively impacted.
- Because of the potential consequences of the wrong data going to the court and being exposed to those in the courtroom, as well as issues related to evidentiary privilege, the provision of data to the court needs to be done with caseworker involvement rather than being automated.
- An electronic system must be able to handle the fact that new authorizations will be needed
  as new caregivers come on board and youth ages, and such authorizations should be
  capable of being handled in an electronic environment, with electronic signatures.

- Access management procedures must ensure that access is granted and terminated appropriately (e.g., when a child is transferred to new placement, former foster parent must lose access).
- Even where the law allows sharing, discretion must be used. For instance, a minor might
  have the right to see information, but before being able to access it, they might be required
  to have a conversation with a trusted adult to help them understand it and/or put it in
  context.

#### **Data Segregation**

An important mechanism for protecting the data is data segregation and tagging such that access to data is specific to the user. The current CWS/CMS accommodates only an "all or nothing" data-sharing scenario that is a barrier to information sharing. The new CWS-NS will need the capacity to share designated information in order to facilitate care coordination through appropriate electronic information sharing.

To properly manage access in the foster care context, data tagging must be adequately granular or the data needs to be compartmentalized effectively. Some issues that were discussed include:

- Tagging could enable the data source to be used to help segment data.
- Tagging could reference type of data (e.g., sensitive) and/or could designate appropriate use (e.g., available only for treatment and coordination).
- To ensure most appropriate tagging, providers will need to be able to tag data at the point of service.
- Particular interest was expressed in making sure that foster parent data is tagged as coming from the foster parent and that it be shared narrowly and only with professionals.
- Tagging presents a workload issue.
- Concerns were raised about what happens when data is tagged incorrectly.

#### **Data Quality**

In the current paper environment, data quality is a concern. When information is automatically populated from linked systems, data quality will remain a concern and requires some form of human review. To address this issue, a number of approaches were discussed.

First, a system should be developed for data reconciliation, which creates data hierarchies between systems and allows for viewing multiple data sets where both sources may be useful. Second, a gatekeeper should be established (along the lines as currently done in CalREDIE). In particular, it was noted that review and clean up of health data requires someone with medical knowledge in order for such data to be useful for health providers, among others. Advocates felt that there is great value in having users submit corrections, where they identify errors. But, an approval process is needed, as well as a record kept regarding the action taken, even when a change is not made. Further, to promote trust of data quality, provenance must be indicated as to this and all other data. Last, PHNs recommend that where health information is entered into the record by providers or PHNs, a back-up hard copy of health records be maintained.

#### **Age of Access**

Youth are entitled to specified information, under California law, and the outfacing tool becomes a natural way to satisfy that requirement. However, because of the nature of the information in the CWS-NS and linked systems, it is clear that access being provided to youth must be done in a manner that takes into account their maturity and ability to handle certain types of information.

The importance of leveraging the electronic resource to provide information to youth themselves rises as they approach emancipation. At 18, foster youth (whether emancipated or not) should gain full access to their records and will need to reissue any authorizations. However, advocates believe that data can be shared with foster youth before age 18. In fact, former foster youth urge that such data be fairly complete, and that they be able to provide input to the record in some manner as well. As they framed it, if their information is being shared with other people (like school counselors and foster parents), it should be shared with them and should reflect their input, too.

Routine involvement with the outfacing tool could happen as early as age 14 (when youth are eligible to participate in the statewide organization for foster youth, California Youth Connection) and at least by age 16, when the AB12 process begins. And, as relevant, support could be provided to help them understand/deal with information to address concerns about maturity. Mental health information is of great concern in this regard and, where there is concern about exposing a minor to information, it might be done in the presence/with support of their dependency attorney, caseworker, or other trusted adult.

#### **User Input**

There is strong consensus that third-party data would be of great value to care, if handled properly. However, it remains an open question as to whether federal SACWIS rules will be changed to allow outside data to flow into the CWS-NS. Advocates made the following suggestions to help clarify a workable process for including such data in the exchange.

- 1. **This and all data must be tagged as to provenance** (as discussed above). For instance, a foster parent's input would be identified as different from a health provider's input and might be subject to different review protocols before being included and/or shared.
- 2. Third parties must not be able to modify existing data, though it is important that they be able to submit corrections that are reflected in the record and incorporated only with proper review (as discussed above).
- 3. There is value to allowing input that goes beyond drop-down menus—and, in fact, health providers request that any online forms allow them to include text, since often the narrow drop-down options leave them unable to provide accurate and useful information.
- 4. Where health information is submitted through hard copy records, such records should be maintained in caseworker files.
- 5. If SACWIS rules are not changed, this non-SACWIS data could still be used to inform health providers and others, alongside the CWS data, without becoming part of the CWS-NS—such as through a foster-care-specific health information exchange. Any outfacing feature to the CWS-NS should be compatible with/able to link with tools that could provide this view of additional, relevant information.

#### **History**

One great value of having more robust data exchange in support of the care of these children and youth is the ability to create a history, which can be very important to understanding a child's needs and to helping a youth gain independence. Health providers, in particular, are eager to have historic health data, including birth data and experience of parental substance abuse and mental illness, and believe it would enhance their ability to provide effective care. In fact, where PHNs have been able to get a transmission of CCS records via secure e-mail, it has been a tremendous resource – and such exchange would seem to make sense in every case, for care management purposes. However, PHNs raised the concern that information that is shared with them, whatever the purpose, has the possibility of being used for purposes other than health care (such as to build a case). In another expression of the challenge, former foster youth express concern that labels and outdated impressions follow them forever, often leading the provider or school counselor to focus more on their history and labels than on the person sitting in front of them.

To limit problems caused by sharing this information, it was proposed that caseworkers be allowed to limit what substitute caregivers can see about a child's history. Further, it was suggested that there be levels of access given, with most viewers receiving only "current" information about health and other issues, but those with a need to review history given access to longer term data. In addition, it was acknowledged that health history information should be exchanged for treatment purposes, though its exchange would be restricted when sought for other purposes, such as when the intent is to establish a case against the biological parents.

#### **Security**

Trust is important to ensuring use of a consumer-facing record. As such, the system will need to meet encryption, identity credentialing, and other technical security requirements. However, it is important that the security layer not get in the way of using the record (i.e., it will need to be user-friendly). In addition, the system should maintain an audit trail.

#### **Mental Health Data**

Mental health information is needed by many members of the care team to support their role. However, who needs what mental health information is hard to define in categorical terms. For instance, schools generally do not need to know the mental health diagnosis, though they may need related information that helps them work with the child most effectively (e.g., dosage of medication that is to be administered during the school day, triggers that may upset the child, time of day that medication would make her sleepy, etc.). To address these nuances, careful use-related limitations regarding the different elements of mental health information (e.g., diagnosis, medication, and treatment) must be implemented.

In setting these parameters, it is felt that foster parents, in particular, require much better mental health information. But, no resolution was reached as to what that would include. Some suggestion was made to limit the mental health data in the outfacing feature to what is required for the HEP: medications, treatment instructions, and information about relevant providers. (Note, in some counties, diagnosis information may also be standard in the HEP and poses concern for some advocates, while others feel it is important information for foster parents to have. In either case, it was acknowledged that using diagnosis codes provides a false sense of confidentiality.) Ideally, where it is deemed important to have additional information, access to an additional layer of detail could be provided upon a showing of need. In addition, to support greater communication, the outfacing tool should provide accurate contact information about health and mental health providers.

Concern was raised that mental health information in the record is often incorrect. It might have been put into the record to support a foster parent in getting a better payment rate or may have been included as a range of issues that were being explored with the intention of removing those that were resolved. Thus, mental health information provides a good example of the challenge to maintaining a clean, accurate record—and the potential consequences of sharing inaccurate information out of that record. It also points to the value of having user review and ability to submit corrections.

#### **Data Sharing With Probation**

Since probation workers now use the CWS system and youth in that system have a HEP, it was noted that probation information held by CWS-NS should be treated carefully in any outfacing feature and should not be shared with schools. Further, advocates wanted to highlight that the existence of broader information sharing and electronic records should not in any way change a youth's right to have their juvenile justice record sealed, where that is the case.

#### **Usability**

Experience with electronic health records, in general, and systems like Foster Focus shows that they are not as likely to be used if they function separately from case management systems. Some suggestions to achieve this integration include: allowing for an interface with a health provider's EMR system and allowing the provider to view across their foster caseload.

In addition, it was noted that the look and feel of a foster parent- and foster youth-facing portal would need to be very different from that provided to a professional and must be presented at an appropriate literacy level. Further, concern was expressed regarding the Digital Divide and the fact that some foster parents will not be able to use/access this tool. Thus, while the electronic system may exist for all families, it is important that a foster parent be able to obtain this information in a paper format if that better suits their needs.

#### **Scalability**

It is important that the CWS-NS be built in a manner that is easily modified and scalable, to the greatest degree possible, in order to guarantee continued relevance over time. For instance, new roles are being explored for CDSS regarding service delivery and tracking for unaccompanied homeless minor youth. As such, the new Child Welfare Services system (CWS-NS) should, at a minimum, be capable of tracking basic information about these youth at both an individual client level and a population level and be able to evolve to further support necessary data collection and support services in the future.

#### **Record Retention**

Records developed with this integrated system should be retained long enough to allow a child who is in and out of foster care to benefit from the historic information. However, advocates worry about how long the records will be available after a child/youth leaves care and urge that some time frame be laid out to ensure that the records are not available to child welfare and other professionals indefinitely. At the same time, this outfacing tool should enable emancipated youth to have access to their own information and documents in an ongoing manner—more than being given a flash drive with copies, which can be lost just as easily as paper documents.

#### Workload

As discussed above, some form of oversight or review is recommended before allowing certain forms of new data to enter the CWS-NS as well as to ensure that data is tagged correctly. This new role poses a workload issue, although there will be some reduced workload as well that accompanies automation. Similarly, oversight will be needed to ensure that appropriate information is shared—much as is done today, through procedures that require a caseworker to redact information before submitting it to the court or other parties. As the system is developed, adequate staffing must be provided to support these important human touches.

## **Conclusion and Recommended Next Steps**

While there are many issues to be resolved to ensure that the data from the CWS-NS is shared appropriately in an outfacing tool, there is much value that such a tool could bring. Thus, California's foster care advocates urge CDSS to develop an outfacing feature as part of the CWS-NS, and to do so in a manner that promotes care coordination, continuity of care at transitions, and youth engagement as they move into independence.

#### **Recommended Next Steps**

- 1. **Convening**. The next logical step in this process would be an in-person convening of state agencies that maintain data about these children, counties that are exploring this concept, and representatives of potential data recipients (such as health providers). The report recommendations could be a useful jumping off point for that conversation.
- Ongoing Stakeholder Meetings. Advocates would welcome a routine, ongoing opportunity
  to discuss the CWS-NS with CDSS as it proceeds through the design and development
  process. The existing quarterly CDSS Advocates meeting does not allow time to get into
  detail about the CWS-NS.
- 3. **Periodic Updates**. Advocates have expressed an interest in receiving periodic updates about the CWS-NS. The Children's Partnership has agreed to provide that, as relevant.
- 4. **Opportunities for Input**. Advocates interested in providing further input and detail than was possible in this report are encouraged to continue to present constructive proposals that help CDSS in planning an outfacing feature to the CWS-NS.

#### **APPENDIX A**

## Individuals and Organizations That Provided Input

#### **Meetings of Stakeholders To Obtain Input for This Report**

April 30	Full Group (in person and by phone)
May 19	Homeless and Other Youth Subgroup
May 21	Foster Care Advocates
May 22	County PHNs Subgroup
May 23	Legal Advocates Subgroup
May 28	Health and Other Providers Subgroup
May 29	County Public Health Nurses Subgroup
May 30	Foster Youth Subgroup
May 30	Legal Advocates Subgroup
June 9	Draft of Report Sent to Full Group for Feedback
June 25	Full Group Discussion of Report

#### **Groups Invited To Participate in This Process**

Invitations to participate in this process were sent to all members of the following groups:

- 1. California State Foster Care Task Force
- 2. Children's Advocates Roundtable
- 3. CDSS Advocates Meeting

#### **Individuals Involved in This Process**

#### Listed Alphabetically

Roberta Bresler-Sullivan, Solano County Child Welfare Services

Carol Brown, California State Foster Care Task Force

Alice Bussiere, Youth Law Center

Katy Carlsen, American Academy of Pediatrics (AAP), Chapter 1, Foster Care Committee

Rachel Clauson, EMQ Families First

Serena Clayton, California School-Based Health Alliance

Reed Connell, Social Change Partners

Erma Coty, Santa Cruz County Human Services

Paul Curtis, California Coalition for Youth

Brenda Dabney, Children's Law Center

Judy Darnell, United Ways of California

Patti Dellacort, Lassen County Child and Family Protective Services

Pat Dorais, Sacramento County Child Protective Services

Sid Gardner, Children and Family Futures

Zoey Goore, AAP, Chapter 1

Becca Gorman, Children's Rights Advocates

Rebecca Gudeman, National Center for Youth Law

Jesse Hahnel, National Center for Youth Law

Juliet Halverson, San Francisco Human Services

Jessica Haspel, Children Now

Vanessa Hernandez, California Youth Connection

#### Continued

Cathy Ishizu, Sonoma County Human Services Doug Johnson, California Alliance for Children and Families Susanna Kniffen, Children Now Phil Ladew, California CASA Martha Mathews, Public Counsel Beth Morrow, The Children's Partnership Anne Nadler, Sonoma County Human Services Dena Proctor, Alameda County Human Services Ginny Puddefoot, The Children's Partnership Margaret Quintana, Shasta County Child Protective Services Fiza Quraishi, National Center for Youth Law Christina Riehl, Children's Advocacy Institute Caryn Romero, Aspiranet Stockton Deborah Rosenberg, Lassen County Child and Family Protective Services Melissa San Miguel, National Center for Youth Law Nancy Shifflet, Shasta County Child Protective Services Sherylin Taylor, Lake County Public Health Anne Trevino, San Francisco Human Services Lori Trigalett, Alameda County Human Services Rachel Weinreb, AAP, Chapter 1, Foster Care Committee Julia Wood, Los Angeles County Children and Family Services

Vonica Yee, San Francisco Human Services

Note: This report reflects the opinions expressed during the advocates meetings and expresses the strong consensus around major recommendations. However, the expression may not reflect these individuals' and their organizations' views about every detail.

#### **APPENDIX B**

## Related Design Issues That Pertain With or Without an "Outfacing Element"

- 1. The new system should be designed to capture better data at the moment of intake/risk assessment. This requires training workers about the importance of this information, as well as a simple user interface with enriched questioning. Examples of such information that are often inadequately recorded include a history of drug and alcohol involvement of biological parents and the child's health history where there are no major medical issues (since such information is generally only gathered where there are pressing medical needs).
- 2. Drop-down menus can create problems by failing to allow for adequately precise choices. Going forward, the need to simplify and standardize data entry through the use of drop-down menus must not trump the need to collect granular, child-specific information. This issue becomes more important if forms like the PM 160 are completed and submitted online by health providers. Health providers must always be able to write some text, even where drop-down menus are the main structure.
- 3. Where a health concern arises, the PHN is often left out of the loop and is forced to request records from colleagues to build a complete file. Often, relevant health documents end up sitting in a paper file and never become part of the HEP. Thus, the process could be improved by giving PHNs direct access to available health record systems, from which they could pull data directly into the HEP. This has been done with CCS and Stanford, allowing PHNs to better coordinate the child's health care.
- 4. Under the current system, it takes so long for information to get into the CWS/CMS that the HEP is often almost empty when a foster parent first takes in a child. With each transition, the HEP tends to lack critical information, and yet that is the time that the HEP could provide the greatest value to continuity and coordination of care.

#### **APPENDIX C**

#### Priority Fixes for CWS/CMS

- 1. The CWS/CMS does not provide a warning when two people are working on a case file at the same time. However, only one of them will be able to save their work. As a result, whoever saves their work first gets data saved, and the other gets all their data wiped out. This happens fairly frequently and is very frustrating. It also makes people hesitant to put data into the system.
- 2. **The CWS/CMS drop-down menus are limited and problematic**. This is particularly true for the options related to health condition and mental/behavioral health, for which the definitions are not very precise. So, a public health nurse is often required to list the item as "other physical condition" or "other emotional condition," both of which provide very little value to health providers and caregivers.
- 3. The process for entering psychiatric medication into the CWS/CMS is problematic due to the requirement for a start and an end date. In fact, an end date may simply indicate the date that a child visits with a new doctor, rather than a change in medication. Instead, where a child/youth is "continuing the same medication," the system should be able to capture it that way.
- 4. The system needs a controlled way to allow authorized staff to remove data in order to clear up a record. An example of how this plays out is presented below (number 5).
- 5. 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 address) that can help differentiate between providers. After entering a physician, this data becomes more easily visible. However, if the PHN identifies that the wrong physician is in the record, at that point they cannot remove that name from it. Thus, the record may have entries for 10 physicians, many of whom are incorrect.
- 6. PHNs experience numerous problems with the drop-down menus and write-in boxes. Specifically, they recommend that the drop-down menus be modified as follows:
  - Medical Test Type: The drop-down menu needs to be expanded, deleted, or changed to a write-in box.
  - Psychiatric Diagnosis: The drop-down menu does not match ICD diagnoses.
  - Well Child Exams: Drop-down menus should be added for BMI and BMI%.
  - <u>Birth History</u>: More space should be provided for the APGARS and in the write-in boxes.
- 7. When PHNs go into the orange block to record a well child exam, the system would work better if the drop-down menu triggered the population of the HEP. Currently, if the PHN does not click "ok," the information is not populated into the HEP. This becomes particularly relevant when dental information is being entered, because PHNs often do not enter the well child section and click "ok" when entering dental data, since they enter the dental data in another section.

Note: The Children's Partnership is in the process of planning another meeting of PHNs to gather input into priority fixes for the CWS/CMS, and will provide that to CDSS when available.