Comprehensive Child Welfare Information System

Toolkit: Engaging Youth in Information Systems Design

The U.S. Department of Health and Human Services Administration for Children and Families (ACF) provides this technical assistance to title IV-E agencies to engage and involve youth in foster care and young adults formerly in foster care (youth and young adults) in the design and development of child welfare information systems, websites, or applications. Title IV-E agencies should consider this population as a "user group" with access to his/her electronic case records, so that they can be more involved in their case, stay connected, and communicate directly with case team members.

This document summarizes the benefits of engaging youth and young adults in system design by providing tips for overcoming common challenges and highlights agency examples. While the document largely focuses on Comprehensive Child Welfare Information Systems (CCWIS), the benefits and examples may be applied to any system, website, or application supporting child welfare practice. *The information and recommendations herein do not establish requirements or supersede existing laws or official guidance.*

This technical assistance document is intended for title IV-E agency program staff, youth in foster care, young adults formerly in foster care, CCWIS project managers, and other child welfare partners. The document is organized as follows:

- **The Case for Involving Youth and Young Adults:** a summary of the advantages of involving youth and young adults in design and development of child welfare information systems, websites, and applications.

- **The Case for Providing System Access:** considerations for allowing youth and young adults to access data in child welfare information systems.

- **Stakeholder Input:** sample user stories shared by youth and young adults for title IV-E agencies to consider when designing a CCWIS and allowing access to data.

- **Case Studies:** Title IV-E agency examples where youth and young adults were involved with information systems design and development.

- **In Conclusion:** Key summary recommendations and additional resources.

The Case for Involving Youth and Young Adults

One of the most promising aspects of federal regulations for CCWIS at 45 CFR §1355.52 (c)(2) and (d)(iv) is the ability of title IV-E agencies to be innovative in their approach towards system development and child welfare practice support. Information systems built to meet requirements of previous versions of the regulations at 45 CFR §1355.50 - 59 focused heavily on data-collection. However, federal regulations for CCWIS support a flexible, modern design that encourage title IV-E agencies to build or purchase information systems to improve service delivery, rather than solely report on actions taken.

The federal regulations for CCWIS support flexibility and innovative technology approaches. One of the most exciting developments in recent system rollouts has been the extension of child welfare information systems to a broader array of user groups. The best way to identify these emerging technologies is to ask the user groups themselves for feedback.[1] Some title IV-E agencies are including youth and young adults as a user group because these agencies recognize the importance of keeping youth engaged and informed.

With these potential features of the CCWIS, it becomes critical for title IV-E agencies to include youth and young adults when gathering requirements for systems as they would any other user group. However, there are some unique challenges with soliciting input from this population. The chart below identifies possible solutions to challenges identified by title IV-E agencies when attempting to engage youth and young adults.

Access to the information in a CCWIS becomes an important tool for youth in foster care and young adults formerly in foster care when addressing:

- **data quality**
- **communicating case actions**
- **sharing information**
- **providing a forum for input**
- **collecting information**
- **transition planning**
- **providing access to important "life" documents**

Challenge	Possible Solution
Locating Young Adults Formerly in Foster Care	There are several national and local foster youth alumni associations that can serve as resources and can provide local connections for particular states or tribes. Title IV-E agencies can also reach out to youth in the National Youth in Transition Database (NYTD) cohorts or work with youth advisory committees and independent living child welfare contributing agencies (CWCA).
Availability of Youth in Foster Care and Young Adults Formerly in Foster Care	Many youth and young adults are either in school or are employed during title IV-E agencies' work hours. Agencies should be flexible and host virtual, evening, and/or weekend sessions to accommodate differing schedule needs. Agencies may also want to consider apportioning youth and young adult involvement to specific topics and/or action items rather than multi-day sessions to make the most of their time.

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[1] Alkhaldi G., Hamilton F., Lau R., Webster R., Michie S., Murray E. The Effectiveness of Digital Interventions: A Systematic Review. Internet Res 2016;18(1):e6

Challenge	Possible Solution
	Agencies should explore opportunities to compensate young adults formerly in foster care within the context of applicable funding restrictions.
Engaging Youth in Foster Care and Young Adults Formerly in Foster Care	Title IV-E agencies can work with independent living providers, foster youth alumni organizations, grantees, and community organizations to transport the youth. Alternatively, agencies can use a phone or video chat for virtual sessions. There are several free or low-cost video chat apps available that have been successfully used to engage remote users. When developing engagement strategies, title IV-E agencies are encouraged to adapt their outreach efforts and experiment with platforms such as smartphone apps and social media. Agencies should be mindful of potential confidentiality and security risks when utilizing social media/smartphones and should consult security and legal specialists, as well as applicable social media policies, when engaging user groups. Agencies may also wish to consider reviewing existing security/confidentiality protocols regularly and make adjustments as needed to meet unique needs of a particular user group. There are several social media platforms to choose from and while Facebook and Twitter receive a great deal of attention in the media, these two platforms are only used by 51% and 32%, respectively, of U.S. teens.[2] YouTube (85%), Instagram (72%), and Snapchat (69%) are currently more widely used by the U.S. teen demographic. Younger teens are increasingly using an assortment of newer social media platforms like WhatsApp, Kik, TikTok, Tumblr, Viber, and Twitch, plus many more.[3]
Coaching and Support	Title IV-E agencies should provide coaching and support to ensure that youth and young adults participating in system requirement-gathering activities (e.g., joint application design sessions, user design sessions/interviews, etc.) understand the project vision and have sufficient understanding of what is being asked of them. Agencies should consider an orientation/onboarding program prior to gathering system requirements as well as a frequently-asked-questions (FAQ) document with definitions and common acronyms to assist participants. The agency can later repurpose FAQs when gathering requirements from other stakeholders like foster parents, providers, and birth families. Youth, young adults, and other stakeholders should not be expected to have up-front knowledge of project management, software development lifecycle (SDLC) or agile/Scrum terminology.

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[2] "Teens, Social Media & Technology 2018." 2018. Pew Research Center.
[3] "Instagram and Snapchat are Most Popular Social Networks for Teens". 2017. The Associated Press.

Challenge	Possible Solution
Communicating Results	Project teams should be mindful of developing a communication and change management strategy to assist youth and young adults in understanding how the agency will actually utilize their feedback and participation to inform the system development process. Sharing expectations about the software development life cycle, target schedules for different processes and expected results is an important part of gaining trust and showing respect to youth and young adults who share their time and skills to improve system responsiveness.
Privacy	Participants in design sessions may share personal details of their life story and title IV-E agencies should take proactive steps to acknowledge and protect the privacy of participants' disclosures and opinions. Agencies may wish to implement standard protocols, such as discussing privacy expectations at the beginning of user exploratory interviews and/or technology design sessions, as well as routinely collecting written privacy acknowledgements from participants.

Changing Technology

Efforts to engage youth and young adults should be made on a continual basis, just as with any other user group. Technology is in a constant state of change and title IV-E agencies should be flexible to address new opportunities and platforms for engagement efforts. Often, the best way to identify these emerging technologies is to ask the young adults themselves. A prime example of the power of youth voice are the eight "Hackathons" held over the past several years which have resulted in multiple tech prototypes, ideas, and policy changes. At these events, youth in foster care and young adults formerly in foster care collaborate with technology experts to think "outside the box" and use technology to improve the foster care experience for young people, foster parents, families, and those who support them.

The Case for Providing System Access

The ability of a youth and young adults to access their case information in a CCWIS becomes an important tool for providing access to information and documents collected during their time in foster care, improving data quality, communicating case actions, sharing information, providing a forum for input, and collecting information. These youth and young adults have an opportunity to become involved in their case, stay connected, communicate directly with the members of the case team, and both access and update their electronic records. They may need information contained in their case records to obtain employment, enroll in higher education, meet medical needs and/or other service needs, and maintain contact with siblings and other family members.

Confidentiality

CCWIS must comply with federal confidentiality provisions at section 471(a)(8) of the Social Security Act, regulations at 45 CFR §1355.30(p)(3), 45 CFR §205.50, and sections 2.1A.1 and 8.4E of the Child Welfare Policy Manual. For all categories of users, title IV-E agencies must also comply with any state or tribal laws and policies that address access to the information contained in a CCWIS or other system.

Title IV-E Agency Responsibilities

It is important to note that confidentiality is a necessary and a critical factor in system design, but should not prevent title IV-E agencies from developing portals, allowing youth and young adults to access their case information, or sharing information electronically with youth and young adults.

When possible, care and consideration should be given to the age and maturity of the youth in foster care when making decisions about which data elements will be shared. Several laws address information that must be shared with youth in foster care; examples are described in the table below. Agencies are encouraged to review federal, and state or tribal policies to ensure outreach strategies align with applicable laws and policies.

Activity	Requirement & Source
Access to Records	Section 475(5)(I) of the Social Security Act requires title IV-E agencies to provide youth who have been in foster care for at least 6 months, and are exiting foster care by aging out, a certified or official copy of his/her birth certificate, Social Security Card, health insurance information, medical records, a state identification card or driver's license, and any official documentation necessary to prove that the youth was previously in foster care. Title IV-E agencies must also provide a copy of the youth's consumer credit report annually, beginning at 14 years of age, until the youth leaves foster care.
Case Planning	Sections 475(1)(B) and 475A(c)(1)(B)(ii) of the Social Security Act requires that with respect to a youth in foster care who has attained age 14 or older, a case plan be developed in consultation with the youth and their case planning team. Additionally, a majority of jurisdictions have laws that require child welfare agencies to include youth in foster care (ages vary by state) in case-planning efforts.[4]

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[4] Case Planning for Families Involved with Child Welfare Agencies. 2018. Retrieved from
https://childwelfare.gov/pubPDFs/caseplanning.pdf

Activity	Requirement & Source
Proof of Foster Care Status	Section 475(5)(I) of the Social Security Act includes a requirement that title IV-E agencies must provide official documentation to prove that an individual was previously in foster care before they are discharged from foster care.
Court Participation	In a majority of jurisdictions, state law or court rules consider youth in foster care a party that the agency must give notice of proceedings related to their case.[5]
Transition Plans	Section 475(5)(H) of the Social Security Act requires title IV-E agencies to provide youth in foster care with assistance and support in developing a personalized transition plan during the 90-day period immediately prior to the date on which the youth will age out of foster care. Transition plans must include specific options on housing, health insurance, education, local opportunities for mentors and continuing support services, and work force supports and employment services.

Commercial-off-the-Shelf (COTS) Products

Some title IV-E agencies may decide to purchase COTS products that meet some or all of the requirements identified by stakeholders. Title IV-E agencies that wish to utilize a COTS product should receive prior approval from ACF with an APD Waiver as described in ACF-OA-PI-13-01, which is available at https://www.acf.hhs.gov/cb/resource/acf-oa-pi1301.

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[5] Engagement of Youth in Court. 2013. Retrieved from http://www.ncsl.org/research/human-services/youth-voice-in-court.aspx

Youth and Young Adult Input

In this section, we share a few User Stories collected from youth and young adults that agencies may wish to consider when designing CCWIS systems, portals, apps, or websites. Collectively, they highlight the desire (and need) for youth to be connected to their case, team, and history.

I would like a portal where I can communicate back and forth with my caseworker and have a record.

I want a user portal where I have easy access to comprehensive information about my rights.

I want to view and retrieve photographs of me and/or my birth family taken by foster parents or caseworkers.

As an alumnus, I want online access to my case along with placement, medical, and educational information.

I want to be able to access a survey tool to submit reviews of foster homes after I leave the placement or on my agency when I age out.

I am in foster care and I want a portal where I have access to current contact information for important individuals other than my caseworker. For example, my caseworker's supervisor, on-call staff, the county or regional director, my CASA worker, etc.

I would like to be able to access and update a shared calendar of upcoming visits, court dates, independent living trainings, and other events.

I would like scanned copies of report cards, art, school work, etc. collected during my time in foster care.

I would like to review and apply for benefits and/or services available to me as a former foster youth without coming into an office.

I would like to complete my NYTD survey online, on my own time, instead of in an office, a car, or over the phone where people can hear me.

I would like to have access to my service and transitional living plans and be able to provide my own updates that can be included in the report to the court.

The user stories noted above are provided, for your convenience and ease of use, in the table below. They highlight what title IV-E agencies may want to consider when designing CCWIS systems, portals, apps, or websites. The following examples all assume applicable confidentiality laws are followed and a secure portal is used by title IV-E agencies.

Category	Brief Explanation of User Story
Benefits & Services	Search and apply for benefits, providers, and/or services without having to come into an office or set an appointment. If an office visit is required, the system/app/webpage should allow the individual the ability to schedule an appointment.
Calendar	Access and update a shared calendar with information on upcoming visits, court dates, independent living trainings, and any other events as needed.
Case Information	Access to case details to view current and historical placement, court, education, and medical/dental information.
Communication	Communicate with the assigned caseworker and maintain a record of previous communications with the current and any previous caseworkers.
Contact Information	Access current contact information for their caseworker, caseworker's supervisor, on-call staff, county or regional director, and CASA/GAL.
History	View and retrieve scanned copies of report cards, art, school work, etc.
NYTD	Complete and submit the NYTD survey.
Photographs	View and retrieve photographs taken by the foster parents and/or caseworkers.
Placements	Access and submit a survey tool to submit reviews of previous placements.
Rights	View and print the bill of rights for youth in foster care (for applicable states and tribes).
Service (Case) Plans	Access current and historical versions of service (case) plans, independent living assessments, and transitional living plans to read and/or provide updates to be included in the report to court.

Case Studies

This section includes state examples of innovative ways to engage youth and young adults in technology development efforts:

Case Study #1

In 2016, the Virginia Department of Social Services (VDSS) began collecting requirements for COMPASS, an information system intended to meet CCWIS requirements. Believing that youth and young adults should be a CCWIS user group, Virginia took steps to ensure that this population was involved in all aspects of gathering requirements and designing the new system.

- In collaboration with Great Expectations, an initiative of Virginia's Community Colleges to empower and support young adults formerly in foster care, VDSS hired a former foster youth who was pursuing an information technology degree to inform and support the design and functionality of the COMPASS program.

- This business analyst coordinated and facilitated CCWIS requirement-gathering sessions with youth and young adults. To accommodate schedules, the business analyst scheduled the sessions for early evenings and coordinated with a VDSS grantee to arrange transportation.

- After requirements for the CCWIS were documented, the business analyst accepted a position elsewhere in the organization but continues to support CCWIS efforts and provide feedback on relevant topics.

Case Study #2

In 2017, the Hawai'i Department of Human Services (DHS), in collaboration with a local nonprofit, created an app and website with resources for youth and young adults. In creating these online resources, DHS consulted with this population to ensure that the app and website met the needs of young adults transitioning to adulthood. These youth and young adults were responsible for defining requirements, creating training videos on how to use the app, and communicating the benefits of the websites and app to Hawai'i's foster care population.

- The app, *Foster Hope Hawai'i*, is available on multiple platforms and provides island-specific information, training calendars, news/updates, service providers, and emergency resources.

- *ShakaTown.com* is Hawai'i's online community to connect and help youth and young adults formerly in foster care. DHS partnered with the University of Hawai'i, Maui College to create this online portal to allow transitioning youth to apply for extended assistance benefits, participate in surveying instruments such as NYTD, and allow youth to store and access documents.

- *ILPCONNECTIONS.org* is a new, centralized resource and has informational videos to explain options for youth and young adults. This online resource was created and launched in 2017 by young adults formerly in foster care who wanted to make the information accessible, and not confusing or overwhelming. The website includes information about youth leadership opportunities, higher education resources, and *Imua Kākou*, Hawai'i's voluntary care program for youth in foster care ages 18-21.

Case Study #3

Ohio has a strong history of collaborating with Youth Advisory Boards (YAB) in utilizing technology solutions to improve service delivery. Several years ago, YAB requested that a state system-generated letter be introduced to document high-level placement-summary information to support Federal Student Aid documentation. Previously, young adults formerly in foster care had to secure copies of court orders to submit with financial aid applications to demonstrate they met acceptance criteria, which was time consuming and overly intrusive in revealing sensitive information.

More recently, Ohio involved young adults when redesigning NYTD survey questions and choosing the NYTD Logo and Survey Information Letter. In addition, young adults are frequently represented in pilot programs, such as the Youth at Risk of Homelessness initiative, to express feedback on how evaluation data are collected and shared with the public.

In Conclusion

Engaging Youth & Young Adults

Title IV-E agencies should include youth and young adults when designing and implementing a CCWIS, website, or mobile application. Regardless of the technology used, title IV-E agencies should consider this population as an essential user group of any information system. As noted in this technical assistance document, providing a youth and young adult with access to his/her electronic case records allows them to become more involved in their case, stay connected, and communicate directly with the members of the case team. While there are some challenges in collecting information from this user group, the challenges are not insurmountable and the benefits far outweigh the risks.

Confidentiality

At times, privacy concerns are cited by title IV-E agencies as a barrier to sharing case information electronically with youth and young adults. As noted in this document, there are indeed privacy considerations that must be addressed. However, these considerations should not be used as a justification to deny all access as title IV-E of the Act requires agencies to share certain information with youth in foster care. In addition, CCWIS regulations at 45 CFR §1355.52 (d)(iv) require that data support child welfare policies, goals, and practices.

Additional Resources

- [Engaging and Involving Youth](#)
- [Podcast: Engaging Youth in Foster Care](#)
- [Tools for Engaging Children in Court Proceedings](#)

Share

If you would like to share an example of how your title IV-E agency has engaged youth in foster care and young adults formerly in foster care when designing information systems, please contact ccwis.questions@acf.hhs.gov.