Children’s Mental Health Initiative

National Evaluation
Data Collection Manual for Child and Family Outcome Study

Grantee Year 2013 2014

Manual
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Purpose

The National SOC Expansion Evaluation for the Children’s Mental Health Initiative (CMHI) is funded by the Substance Abuse and Mental Health Services Administration (SAMHSA) for all System of Care (SOC) Expansion grants. The purpose of the National Evaluation’s Child and Family Outcomes Study is to describe characteristics of youth, young adults, and families who are receiving system of care (SOC) services in expansion grantees sites and track their outcomes over time. Expansion Implementation Grants funded in FY2013 and FY2014 will participate in the Child and Family Outcome Study.

The Child and Family Outcomes Study is designed to:

- Describe how grantees are implementing and expanding SOC at multiple levels
- Examine what approaches and mechanisms are related to successful implementation and expansion
- Describe the individual and family characteristics of youth and families receiving services in SOC expansion sites
- Track how youth and family outcomes and experiences change over time

The goal is to collect Child and Family Outcomes Study data on all eligible and consenting youth and caregivers receiving services within a SOC expansion grant site.

Data Collection Components

Grantees are responsible for interviewing youth/young adults and primary caregivers using the Child and Family Outcomes tools (see Table 1) to collect background information and longitudinal data on child/youth/young adult clinical and functional outcomes, as well as family outcomes. Grantees also are asked to collect descriptive information obtained from the client’s record regarding demographic data on the child and young adult as well as information about the caregiver and child/young adult diagnosis.
Table 1. Child and Family Outcomes Tool Components

<table>
<thead>
<tr>
<th>Component</th>
<th>Information</th>
<th>Time to collect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Background/Administrative data</td>
<td>Admissions, demographic and service data</td>
<td>12 minutes</td>
</tr>
<tr>
<td>Family/Living Information</td>
<td>Household composition</td>
<td>3 minutes</td>
</tr>
<tr>
<td>Caregiver Strain Questionnaire (CGS-17)</td>
<td>Caregiver experience</td>
<td>7 minutes (13 items)</td>
</tr>
<tr>
<td>Columbia Impairment Scale (CIS)</td>
<td>Psychosocial functioning</td>
<td>5 minutes (13 items)</td>
</tr>
<tr>
<td>Pediatric Symptom Checklist 17 (PSC-17)</td>
<td>Behavioral health</td>
<td>3 minutes (17 items)</td>
</tr>
</tbody>
</table>

The components listed in Table 1 have been clustered in tools designed expressly for three respondent populations: 1) caregivers of children ages 5 to 17; youth ages 11 to 17; and young adults ages 18 to 21. All three versions begin with an administrative section that is collected from the client record by agency staff. The remaining four components are obtained by interviewing the respondents as indicated in Table 2. (See the appendices for complete versions of each tool.)

Table 2. Survey Components by Respondent Category

<table>
<thead>
<tr>
<th></th>
<th>Caregivers of children ages 5 to 17</th>
<th>Youth ages 11 to 17</th>
<th>Young adults ages 18 and older</th>
<th>Clinical Staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Background/Administrative data¹</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Family/Living Information²</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Caregiver Strain Questionnaire (CGS-17)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Columbia Impairment Scale (CIS)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Pediatric Symptom Checklist 17 (PSC-17)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
</tbody>
</table>

¹ Background/Administrative questions are gathered by staff from client records.
² Family/living information questions differ in the Caregiver and Young Adult version of the tools.

When Data Are Collected

Specific background/administrative data questions are collected only once, at baseline, specifically questions on the date that the child/young adult was first assessed for system of care, the date of the child/young adult’s first service received through the system of care, the date of the child/young adult’s most recent service planning team meeting in the system of care, who participated in the development of the child/young adult’s service plan, which agency or individual referred the child/young adult to the program, and what led to the child/young adult being referred for services. All other components are collected at baseline, and at reassessment at 6 and 12 months or discharge (whichever comes first).
<table>
<thead>
<tr>
<th>Data collection</th>
<th>Collection Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline</td>
<td>■ Baseline data should be collected within 30 days of the youth first receiving SOC services.</td>
</tr>
<tr>
<td></td>
<td>■ If a new episode of care is initiated because the youth re-enters treatment after a discharge or has a lapse in treatment for 90 days or more, a new baseline interview should be conducted.</td>
</tr>
<tr>
<td></td>
<td>■ If a youth is already receiving SOC services when the National Evaluation data collection begins, data collection should proceed as a baseline record.¹</td>
</tr>
<tr>
<td>Reassessment at 6 and 12 months</td>
<td>■ Reassessments should be completed at 6 and 12 months after the baseline data collection.</td>
</tr>
<tr>
<td></td>
<td>■ Data may be collected 30 days before, or 30 days after, the 6- or 12-month target date.</td>
</tr>
<tr>
<td>Discharge</td>
<td>■ Regardless of the time since baseline, a discharge interview should be performed when the youth is officially discharged from services.</td>
</tr>
<tr>
<td></td>
<td>■ The discharge interview should occur on or immediately following the last day services are received.</td>
</tr>
</tbody>
</table>

¹ As the Evaluation will also collect first date of service, we can distinguish these records from others.

**How the Data Will Be Used**

The National Evaluation Team will create several reports for SAMHSA Center for Mental Health Services (CMHS) to meet federal requirements including a *Report to Congress*, annual evaluation reports, and other ad hoc reports as requested. Aggregated child and family data will be used to complete reports and presentations on behalf of SAMHSA to summarize findings from the National Evaluation. At no time will personally identifiable information be shared. The National Evaluation Team may also prepare site-specific or cross-grantee reports to help disseminate the findings from the study.

**Benefits of the Evaluation for Grantees**

Grantees also benefit from the information received through the National Evaluation. The evaluation can help grantees:

- Understand the results of their efforts
- Identify effective processes, programs, and activities
- Obtain practical suggestions for SOC expansion implementation
- Understand specific ways in which children improve

As a grantee, you will have access to the data that you report for the evaluation. Data may be used for your own analysis, reporting, and quality monitoring. Evaluation findings may be used locally or nationally to leverage funding for systems of care. Demonstrating the positive impact of program efforts encourages support from funders.

**How the National Evaluation Differs From NOMs**

It is important to be aware that all CMHI grantees are required to collect two sets of data. Government Performance and Results Act (GPRA) National Outcomes Measurement System (NOMs) (also called the NOMs Client-Level Measures for Discretionary Programs Providing Direct Services) are required performance measures collected by grantees that are funded by the CMHS within SAMHSA. The National Evaluation Team will have access to the NOMs data you enter to streamline data collection and reduce your workload. Grantees will not have to collect the same questions twice from youth, young adults, or families for the two data collection efforts (NOMs and the National Evaluation).

In addition, grantees are also required to collect data (as described above) for the National Evaluation. Grantees can begin collecting data on paper or through local data collection media. Grantees will receive training on entering data into the online CMHI Portal.

NOMs data requirements, processes, and implementation status are different and separate from the National SOC Expansion Evaluation. The National SOC Evaluation Team is **not** involved with NOMs implementation. Your SAMHSA GPOs are the best contacts for you to address NOMs-related questions and concerns.
Institutional Review Board (IRB)

What Is an Institutional Review Board (IRB)?

IRB stands for Institutional Review Board. An IRB is a specially constituted committee established to protect the rights and welfare of human subjects who participate in research projects. The charge of an IRB is to weigh risks and benefits of participation in research. All research involving human participants must be reviewed and approved by an IRB prior to beginning the research. Based on whether or not your data collection is deemed “research” by your organization, you may or may not need to seek IRB approval.

Do We Need to Get IRB Approval for the Child and Family Outcomes Study?

Yes, you should consult with a local IRB about what is required in your system. In some cases, grantees’ local IRBs have determined that IRB approval is not required for the Child and Family Outcomes Study because collection of the child- and family-level data does not meet the federal definition of “human subjects research,” and they are therefore exempt from IRB review. In other cases, informed consent to participate in the National Evaluation’s Child and Family Outcomes Study may be a part of a system’s consent procedure and additional IRB approval is not required. Other times, IRB approval is required for the Child and Family Outcomes Study because local IRBs determine that it does qualify as research. A local IRB can help determine what is necessary in your system.

From Whom Should We Get IRB Approval?

Grantees can obtain IRB approval from federally registered IRBs for local data collection processes. Most clinics, universities, hospitals, or other service agencies have some type of IRB. For example, a community mental health center involved with collecting Child and Family data may want to seek IRB approval from a regional or State oversight entity for the agency (e.g., State department of mental health). If the evaluation will be contracted to a university or other independent entity, and information will be collected by interviewers hired through the university, then it may be necessary to obtain approval from that university’s IRB. In some cases, several agencies share one IRB or seek approval from State-level or commercial
Boards. If no local IRB exists, it may be necessary to locate a federally registered IRB that can review and approve the evaluation. You may want to check with members of your staff to see if they have any current or prior relationships/affiliations with universities or public/private research organizations that may have access to an IRB for consultation. Otherwise, commercial IRBs are available to provide consultation.

**What Documentation Does the National Evaluation Need About Local IRB Requirements?**

If you are seeking IRB approval for the Child and Family Outcomes Study, please submit your IRB authorization letter to the National Evaluation Team prior to data collection. If it is determined that you do not require IRB approval in your system, please provide written documentation (a brief email to your Site Liaison is fine) about why you are not seeking IRB approval.

**Where Can We Get Consent and Assent Forms?**

To aid you in preparing your IRB applications, sample consent and assent forms may be found in Appendix D. These forms should be customized for your own system and context. The National Evaluation Team can provide technical assistance to support the process, as requested.

**Participants, Enrollment, and Data Collection**

Data collection for the Child and Family Outcomes Study will be coordinated and conducted by grantee staff. The goal is to collect Child and Family Outcomes Study data on all children, youth, young adults, and caregivers receiving services within a SOC expansion site. Figure 1 illustrates a sample process in which families could be enrolled in the Child and Family Outcomes Study. In general, enrolling a family into the National Evaluation may involve the following steps, which should be adapted to your internal process:

- Determine eligibility for the Child and Family Outcomes Study
- Recruit caregivers, if applicable
Figure 1. Sample Enrollment Process into the Child and Family Outcomes Study

- Obtain informed consent and/or assent
- Schedule baseline interview

Determining Eligibility for the Child and Family Outcomes Study

To be included in the evaluation, youth respondents will need to:

- Receive services within a local service system of a funded expansion SOC grant
- Be age 5 to 21 years old
- Have a behavioral health diagnosis
- Have a participating caregiver if the youth is age 5 to 17 years old
- Have baseline data collected within 30 days of entry into service system
- Have completed NOMs measures (also called the NOMs Client-Level Measures for Discretionary Programs Providing Direct Services), and
- Provide informed consent/assent prior to the initial interview, as appropriate based on client age
Clients who are already receiving SOC services may also be enrolled. Eligibility for participation may be assessed using information from the client record.

**Recruit Caregivers**

Children/youth may have multiple caregivers who may be able to participate in the caregiver interview. The primary focus in selecting a caregiver is to obtain the best account of the child/youth’s behavior and functioning. A caregiver should be familiar with the child’s everyday routines and behaviors. Caregivers who participate in the interview could include, but are not limited to:

- Family members/relatives
- Foster parents
- Friends of the family

Caregivers may change over time and different respondents may be interviewed for baseline and for follow-up interviews. Only one adult respondent should participate in the caregiver interview for a particular data collection point. In other words, the respondent may change over time, but only one respondent should participate at each interview (e.g., baseline, 6 months, 12 months).

If a youth receiving services is not living with their legal guardian but is located in a residential setting or out-of-home placement, caregivers may still participate if they have had enough contact to be knowledgeable about the youth. If a youth receiving services is in the custody of the State and no caregiver is available, you do not have to conduct caregiver interviews with staff who are involved with the youth—there are no staff-as-caregiver interviews. If a youth in State custody has a caregiver who knows them well enough to respond to the questions (e.g., a foster parent or parent of origin who has physical custody but not legal custody), that caregiver could participate as long as whoever has legal authority provides consent.
**Obtain Informed Consent**

A participant must provide consent or assent in order to participate in the Child and Family Outcomes Study. Sample consent and assent forms, which may be tailored as needed, may be found in Appendix D.

Caregivers and young adults (ages 18-21) receiving services must provide consent to participate. If the youth is age 11-17, the youth’s legal guardian must also provide permission for the youth to participate. Youth receiving services (ages 11-17) must provide assent. The caregiver must be present when the assent form is introduced to the youth.

SAMHSA has not authorized the National Evaluation to provide compensation or incentive payments for participation in the Child and Family Outcomes Study. If you are able to compensate participants, you may do so. If compensation is provided to participants, this should be specified in the informed consent forms.

**Schedule Interviews**

Schedule youth and caregiver interviews on the same day, when possible. If scheduling does not permit, schedule the interviews as close together as possible. Youth and caregivers should be interviewed separately to protect confidentiality. If time is a constraint, then the interview may be conducted over multiple sessions.

**Participant Protections**

Staff involved in the Child and Family Outcomes Study will have access to personal information about participants and must understand that all data collected is private. It is important to develop procedures to protect participants’ privacy during data collection and with data storage. You also have the option of obtaining a Certificate of Confidentiality, authorized by Section 301(d) of the Public Health Service Act. This certificate adds a level of protection against disclosure of identifying information about participants.
Data Collection and Data Entry Processes

You should assign participants enrolled in the Child and Family Outcomes Study the same ID number as the ID number used for the NOMs for that family. That will assist in linking NOMs information to data collected for the National Evaluation. Data transferred to the National Evaluation Team will not include personal information but will use this unique identifier to protect participant privacy.

Grantees will receive training on the electronic data-entry system in the CMHI Portal. At that point, you will have the option of using the web-based portal to enter the data directly during the interview, or collecting the data via a paper instrument and then entering the data into the system at a later time. All hard-copy interview forms and data should be stored in a locked filing cabinet. All data entered into the CMHI portal is stored behind a password-protected security system, and only authorized users will have access to the system.

Children, youth, and young adults may leave and re-enter services over the period of grant funding. Since only identification numbers (not names) are attached to the Child and Family data, it may be difficult to determine whether data were previously obtained and reported at an earlier intake date. In this case, it is important to maintain a system that recognizes children, youth, and young adults who previously participated and re-enter the system so that multiple unique identifiers are not created for these participants.

Distress Protocol

As the Child and Family Outcomes Study is focused on youth and young adults with severe emotional disturbances (SED), it is necessary to ask questions that are potentially sensitive. The National Evaluation is not introducing new, sensitive domains of inquiry, but is paralleling standard procedures in the field of children's mental health. It is possible that the information collected during the interviews with caregivers, young adults, and youth may cause interviewees to become uncomfortable or experience distress. A distress protocol will be important to have in place if and when these situations arise. If needed, the following is a sample distress protocol that could be adapted to your own SOC. This is a sample and is not meant to replace your own processes or clinical judgment.
Location of Interview

Local program staff should hold interviews in a safe, private space. Privacy should be secured prior to the start of the interview. No other party should be able to hear the discussion outside of the room. The interviewer will suggest that the door (if any) to the private space remain ajar if it will not compromise privacy, particularly if there are no windows in the space.

How to Recognize Distress

Low to Moderate Distress. The interviewee is showing any of the following signs of low to moderate distress with no perceived or expressed threat to their own safety or the safety of others:

- Crying
- Change in mood
- Change in tone
- Trembling or shaking voice
- Allowing distractions frequently
- Signs of intense fear or sensation of being trapped
- Experiencing flashbacks

The interviewer will ask a question to assess the situation such as, Are you okay?, How are you doing?, Do you have any questions?, Would you like to continue or stop?

- If the interviewee responds with “okay,” the interview will continue.
- If the interviewee does not respond or says something to indicate distress, the interviewer will ask if they need a short break or need to stop the interview.
- If the interviewee does not want to stop the interview, the interviewer will continue.
If the interviewee would like a break or wants to stop the interview, the interviewer will take a break and then reassess by asking if the interviewee would like to continue.

- If they say yes, the interview can begin from where it left off.
- If they say no, the interviewer will thank them and ask if they would like to continue the interview at a later date.

**Elevated emotional state.** The interviewee is showing any of the following signs of extreme distress, such as is expressing intent to self-harm or harm others:

- Uncontrollable crying
- Emotional outbursts
- Speaking but not making any sense
- Being disassociated
- Experiencing flashbacks that continue through course of interview
- Plans to hurt or kill themselves
- Statements indicating they might hurt or kill themselves
- Statements indicating they have no reason to live or life has no purpose
- Plans to hurt or kill someone else
- Statements indicating they might hurt or kill someone else
- Statements about planning or thinking about using a weapon
- Statements about ongoing abuse/neglect

If an interviewee is showing signs of an elevated emotional state, the interviewer should stop the interview and say, “It seems you are upset and it may be helpful to stop the interview.” At this point, they should enact their program’s safety plan in order to assist the interviewee.

The following questions are asked in the caregiver or young adult protocols. If the answer to any of the questions below is “yes,” then please use your own system’s safety planning procedures:
Caregiver Interview

- Has your child ever tried to kill himself/herself? (baseline)
- At any time in the past 6 months (including today), did your child seriously think about trying to kill himself/herself? (reassessment)
- During the past 6 months (including today), did your child try to kill himself/herself? (reassessment)

Young Adult Interview

- Have you ever tried to kill yourself? (baseline)
- At any time in the past 6 months (including today), did you seriously think about trying to kill yourself? (reassessment)
- During the past 6 months (including today), did you try to kill yourself? (reassessment)

Availability of Data

Using the CMHI data entry portal will give you access to the data you report. You may download data for service planning, quality improvement and other internal needs. The National Evaluation Team will also send scored data as requested.
Submitting Child and Family Data Through the CMHI National Evaluation Portal

What is the CMHI National Evaluation Portal?

The CMHI National Evaluation Portal (the portal) is the online data entry system that grantees will use to submit data for the National Evaluation. The portal is the place to enter Child and Family Outcomes Study data.

The following sections provide an overview of how to navigate through the portal to access commonly used functions. Below you will find step-by-step instructions on:

- How to access the CMHI National Evaluation Portal
- How to designate someone as an Alternative Project Director in the portal
- How to access and update information on the My Account page
- How to enter data for a baseline interview
- How to enter data for a reassessment or discharge interview
- How to submit data to the National Evaluation Team
- How to access data you have entered into the portal
- Where to go with questions

How to Access the CMHI National Evaluation Portal

Access for Project Directors

1. The portal is set up so that initially Project Directors of all expansion grants have access to the portal.

2. The Project Director will receive two emails from the “CMHI Evaluation.” One email provides a URL for the National Evaluation portal, and the other email has the Project Director’s unique username and password.
3. Once you click on the URL to the portal homepage, click on the “Login” section of the page.

4. Then enter the username and password sent through emails to the Project Director.
5. Once Project Directors log into the system with their user names and passwords, they can go in and allow other users access to the system.

How Project Directors Can Approve User Access in the Portal

1. Click on the “My Account” section and go to “Manage Accounts.”

2. Go to the “Requests for Access” section of the page and click on “Approve” next to the names of people who require access.
How New Users Can Access the Portal

Grant staff members who are not currently in the system can also obtain access through the portal.

1. Staff members should click on “Sign Up” on top banner of the portal homepage.

2. Then click on “Grantee Sign Up” and the following page will appear. Staff should enter in the “Grant ID” and the 32-character “Grant Security Key,” and click “Lookup.”
3. Below is an example of a Grant ID and Grant Security Key. The actual codes associated with each grant were emailed to Project Directors the week of August 8th. These codes should only be shared with staff who require access to the portal.

Grantee Sign Up Form

Enter your Grant ID and Security Key and then click Lookup:

Grant ID: SM00000 Grant Security Key: 2c1cc8f15a694277c1b11b644c66832x

Review to confirm you have entered the correct Grant ID. Repeat these steps if access to another grant is needed.

<table>
<thead>
<tr>
<th>Grant Number</th>
<th>Project Director</th>
<th>Grant Title</th>
<th>Organization</th>
<th>Org City</th>
<th>Org State</th>
</tr>
</thead>
<tbody>
<tr>
<td>SM00000</td>
<td>CF Test</td>
<td>CF Testing</td>
<td>Testing</td>
<td>Rockville</td>
<td>MD</td>
</tr>
</tbody>
</table>

4. Staff requesting access should enter in their contact information and click “Submit.”

Grantee Sign Up Form

Enter your Grant ID and Security Key and then click Lookup:

Grant ID: SM00000 Grant Security Key: 2c1cc8f15a694277c1b11b644c66832x

Review to confirm you have entered the correct Grant ID. Repeat these steps if access to another grant is needed.

Enter contact information below and click Submit

First Name: 
Last Name: User 2
Email Address: testuser2@avestat.com
Confirm Email Address: testuser2@avestat.com
Phone #1: Area Code 301 Number 9999999999 Ext
Phone #2: Area Code Number Ext
Phone #3: Area Code Number Ext
Subscribe to Listserv: YES

Submit Cancel
5. The Project Director will then receive an email indicating that the staff member has requested access. The Project Director can then go into the system and approve the request.

6. The grant staff requesting access will also receive an email confirmation.
Designating an Alternative Project Director to Help Manage Requests

Project Directors may not have time to manage account access on the portal, so each Project Director has the option to designate an “Alternative Project Director” in the portal. This may be a local evaluator or someone more closely monitoring the data collection process. As an Alternative Project Director, this person will have the same administrative rights in the portal as the Project Director. Therefore, they will be able to add people to the system and approve requests to access the portal.

To designate an Alternative Project Director:

1. Project Directors would go to the “My Accounts” tab and select “Manage Accounts.”
2. If the person to be designated as the Alternative Project Director is already listed as a Current User (as indicated below), simply select “Alt PD” and hit “Submit.”
3. If the person you would like to designate as the Alternative Project Director is listed as an Inactive User, click on the check box that says “Reactivate” and hit “Submit.” Once they are listed as a Current User, simply go the drop down box under “User Role” next to the name, select “Alt PD,” and hit “Submit.”
4. If the person the PD would like to designate as an Alternative Project Director is not listed in the system, then you can add them into the system by clicking on “Sign Up” and following the directions noted above to add them into the system.

Viewing and Updating My Account Information

1. Users can view the information in the system about the grant on the “My Account” page under “My Profile Page.”
2. If you would like to update your contact information, click on the “Update my Info” tab. Edit the information and click “Submit.”

How to Enter Baseline Interview Data

1. To enter data from a baseline interview, click on the “Data Entry” section, and then click on the “Child and Family” drop-down menu.
2. Under the “Consumer Records Section,” click on one of the three options for baseline interviews:

- Add Caregiver Baseline
- Add Child Baseline
- Add Young Adult Baseline

How to Enter Reassessment and Discharge Interview Data

1. The “Find Interview” section at the top of the page will allow you to review interview data that has already been entered into the system.
2. Enter a Consumer ID and select “Find.” You may also enter the baseline interview date if available. You will see all the interview records associated with that Consumer ID.

3. After you have found the interviews associated with a specific Consumer ID, you can add a reassessment or add a discharge interview. You can also view, edit, or delete an existing record.
How to Enter Data Into the Portal

1. Once you start a new baseline entry the first screen you will see is the administrative data section.

2. The first field to enter is the Consumer ID.
   
   – The same Consumer ID is used for a caregiver and a corresponding youth, as it links the two interviews.
   
   – The Consumer ID is currently the same ID used for the NOMs.
   
   – The same Consumer ID is used across all episodes of care.

3. Notice the action buttons to the right under the top menu bar. Use these to Print, Cancel, Save, or go to the Previous or Next screen. Once you have entered the data for a screen, select “Next” to advance. Use the “Next” and “Previous” buttons instead of using the “Back” button on your browser. If you do not, you will get a “Webpage Expired” error message and the data will be lost.
Census Block

1. Part of the Administrative Data requested is the Census Block.

2. You do not need to know the actual Census Block number. Once you enter a youth or young adult’s address, select “Submit” and the system will calculate the Census Block.

3. Once you advance and click “Next,” the street address disappears and only the Census Block remains. The street address information never remains in the system.

4. We understand that depending on your system, obtaining a child or young adult’s address may not be possible. If this is the case, click the drop-down box here indicating that these data are missing.

Diagnosis

1. The Administrative Data section also asks for a young person’s diagnosis. There are fields for primary, secondary, and additional diagnoses.

2. Start with the Primary Diagnosis. You must include the classification system that you are using: DSM-IV TR, DSM-V, or ICD 9.
3. Then enter the diagnostic code associated with a diagnosis and click the “Submit Primary Diagnosis” button. Once you do that the diagnosis and the code will auto fill at the bottom of the page. Note: You do not enter data in the fields at the bottom of the screen. These fields auto fill depending on the code you enter in the primary diagnosis section in the middle of the screen.

Submit Data to the National Evaluation Team

1. After you have finished entering interview data into the portal for a specific respondent, the portal will provide you with a summary of all the data that you have entered.

2. After you have reviewed the information and are ready to submit, click on the “Finish” button.

3. This will save the record in the system so you can go back and access it later. The system will not save partial records, so you will need to have all of the information needed for an interview record in order to enter it into the system.
Accessing Data Entered in the System

1. Once you have entered data into the portal, you will be able to get an Excel file with the data for analysis purposes.

2. To access an Excel file of entered data, send an email to your site liaison or to cmhieval@westat.com. In your email, please include the name of your grant.

3. Indicate the data you would like to see and we will send the data to you.
4. You can also download the data directly from the portal website after it has been entered in the system. Simply click on the “Data Download” section and click on “Child and Family.” This will give you the option to download an excel file with all the Child and Family data that have been entered in the system.

Final Tips

1. Internet Explorer is the recommended browser. You should be able to use Chrome or Firefox, but you may have minor layout issues.

2. We strongly advise against entering the Child and Family data using a tablet or smartphone.

3. There is a timeout feature if the system has been idle for 30 minutes.

Questions?

If you have questions or problems with data entry, please send an email to cmhieval@westat.com or contact your site liaison and we will address your concerns.
Appendix A

Caregiver Tools
CHILDREN’S MENTAL HEALTH INITIATIVE
NATIONAL SYSTEM OF CARE EXPANSION EVALUATION

CHILD- AND FAMILY-LEVEL INSTRUMENTS

Public Burden Statement: An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. The OMB control number for this project is 0930-0349. Public reporting burden for this collection of information is estimated to average 23 minutes per respondent, per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to SAMHSA Reports Clearance Officer, 5600 Fishers Lane, Room 15E57-B, Rockville, Maryland, 20857.
INTRODUCTION

Thank you for your willingness to participate in the Child and Family Outcomes Survey. The purpose of this survey is to assess changes in the mental health and well-being of children and their families while they are participating and receiving services from the Systems of Care.

CONFIDENTIALITY/INFORMED CONSENT

Your responses to these questions will be kept confidential and will not be shared outside of the evaluation team. In any of our reports, your responses will be combined with other people’s responses, so your answers will never be attributed to your name. Please sign the consent form prior to completing this questionnaire.
INSTRUCTIONS

This version will be administered to the caregiver of children ages 5 to 17 at every data collection time point unless otherwise noted.

1. Subsection 1: Administrative Data
2. Subsection 2: Family/Living Information
4. Subsection 4: Pediatric Symptom Checklist-17 – self report
5. Subsection 5: Caregiver Strain Questionnaire

There are two components of this instrument. Subsection 1 is answered by staff using information from administrative and clinical records for the child receiving services. Subsections 2-5 are to be administered verbally to the caregiver by local systems staff.
RECORD MANAGEMENT

[RECORD MANAGEMENT IS REPORTED BY GRANTEE STAFF AT BASELINE, REASSESSMENT, AND DISCHARGE REGARDLESS OF WHETHER AN INTERVIEW IS CONDUCTED.]

Consumer ID |________|________|________|________|________|________|________|________|________|________|

Grant ID (Grant/Contract/Cooperative Agreement) |________|________|________|________|________|________|________|________|________|________|

1. Indicate Assessment Type:

- **Baseline**
  - [ENTER THE MONTH AND YEAR WHEN THE CONSUMER FIRST RECEIVED SERVICES UNDER THE GRANT FOR THIS EPISODE OF CARE.]
  - | | / | | |
  - MONTH YEAR

- **Reassessment**
  - Which reassessment?
  - | |
  - [ENTER 06 FOR A 6–MONTH AND 12 FOR A 12–MONTH.]

- **Clinical Discharge**

2. Was the interview conducted?

- **Yes**
  - When?
  - | | / | | |
  - MONTH DAY YEAR

- **No**
  - Why not? Choose only one.
  - □ Not able to obtain consent from proxy
  - □ Consumer was impaired or unable to provide consent
  - □ Consumer refused this interview only
  - □ Consumer was not reached for interview
  - □ Consumer refused all interviews
SUBSECTION 1: ADMINISTRATIVE DATA

[SUBSECTION 1 IS COMPILED BY GRANTEE STAFF FROM RECORDS.]

1. Is the child enrolled in the CMHI Outcome Evaluation?
   - Yes [IF THIS IS A BASELINE, GO TO SUBSECTION 1, QUESTION 2. OTHERWISE SKIP TO SUBSECTION 1, QUESTION 6.]
   - No [STOP HERE.]

2. What is the date of the child's...
   2a. First assessment for the system of care?
       □ | □ | □ / □ | □ | □ | □
           Month       Day       Year
   2b. First service (after assessment) received through the system of care?
       □ | □ | □ / □ | □ | □ | □
           Month       Day       Year
   2c. Most recent service planning team meeting in the system of care?
       □ | □ | □ / □ | □ | □ | □
           Month       Day       Year
Subsection 1: Administrative Data (Continued)

3. **Who participated in the development of the child’s service plan? [Select all that apply and specify role as noted.]**

   - Child’s caregiver or guardian
   - Child
   - Other family member
   - Case manager/service coordinator
   - Wraparound facilitator (if not case manager/service coordinator)
   - Therapist
   - Other mental health staff (e.g., behavioral aide, respite worker) *(Specify role: ___________________)*
   - Intellectual disabilities provider
   - Family advocate
   - Parent/Peer support provider
   - Youth advocate
   - Youth/Peer support provider
   - Education staff (e.g., teacher, counselor) *(Specify role: _____________________________)*
   - Child welfare staff (e.g., case worker) *(Specify role: _____________________________)*
   - Juvenile justice staff (e.g., probation officer) *(Specify role: _____________________________)*
   - Physical health staff (e.g., pediatrician, nurse) *(Specify role: _____________________________)*
   - Other *(For up to three people) *(Specify role: _____________________________)*
     *(Specify role: _____________________________)*
     *(Specify role: _____________________________)*

4. **Which agency or individual referred the child to the program?**

   - Mental Health Agency/Clinic/Provider
   - Physical Health Care Agency/Clinic/Provider
   - Substance Abuse Agency/Clinic/Provider
   - Intellectual Disabilities Agency/Clinic/Provider
   - School/Educational Facility/Staff
   - Early Intervention
   - Child Welfare/Child Protective Services
   - Family Court
   - Juvenile Court/Corrections/Probation/Police
   - Caregiver
   - Youth/Child referred himself or herself
   - Other *(Please specify: _____________________________)*
5. **What led to the child being referred for services? [Select all that apply.]**

- Conduct/delinquency-related behaviors (including physical aggression, extreme verbal abuse, non-compliance, sexual acting out, property damage, theft, running away, sexual assault, fire setting, cruelty to animals, truancy, police contact)
- Intellectual disabilities
- Hyperactive and attention-related behaviors (including hyperactive, impulsive, attentional difficulties)
- School/Educational performance
- Depression (including major depression, dysthymia, sleep disorders, somatic complaints)
- Anxiety (including fears and phobias, generalized anxiety, social avoidance, obsessive-compulsive behavior, post-traumatic stress disorder)
- Adjustment-related issues (including changes in behaviors or emotions in reaction to a significant life stress)
- Suicide-related thoughts or actions (including suicide ideation, or suicide attempt)
- Self-Injury (self-injurious behavior, hair pulling, cutting, etc.)
- Psychotic behaviors (including hallucinations, delusions, strange or odd behaviors)
- Substance use, abuse, and drug dependency behaviors
- Learning disabilities
- Eating disorders (including anorexia, bulimia)
- Sleeping problems
- Current home unable to meet child’s needs
- Maltreatment (child abuse and neglect)
- Behavioral concerns (including aggression, severe defiance, acting out, impulsivity, recklessness, and excessive level of overactivity)
- Excessive crying/tantrums
- Persistent noncompliance (when directed by caregivers/adults)
- Pervasive developmental disabilities (including autistic behaviors, extreme social avoidance, stereotypes, perseverative behavior)
- Specific developmental disabilities (including enuresis, encopresis, expressive or receptive speech and language delay)
- Separation problems
- Feeding problems (including failure to thrive)
- Excluded from preschool or childcare due to behavioral or developmental problems
- Attachment problems
- Other concerns/issues that are related to child’s health (cancer, illness, or disease related-problems)
- Other (Please specify: ________________________________ )
Subsection 1: Administrative Data (Continued)

6. With which of the following agencies is the child involved? [Select all that apply.]

- Mental Health Agency/Clinic/Provider
- Physical Health Care Agency/Clinic/Provider
- Substance Abuse Agency/Clinic/Provider
- Intellectual Disabilities Agency/Provider
- School/Educational Facility
- Early Intervention
- Child Welfare/Child Protective Services
- Family Court
- Juvenile Court/Corrections/Probation/Police
- Other (Please specify: _________________________________)

7. During the past 6 months, was the child insured through...? [Select all that apply.]

- Medicaid
- CHIP
- SSI
- Private Insurance
- Other (Please specify: _________________________________)
- No insurance

8. What is the census block group of the address where the child currently lives?
   __________________

Please note: To obtain the census block group of the consumer, you will need the consumer’s address. This should be obtained from consumer records. The address must be entered into the system to generate the census block; however, the system will not save the address of the consumer, only the census block group.

9. What is the date of the child’s most recent diagnostic evaluation?

|___|___| / |___|___| / |___|___|___|___|
Month Day Year

10. Which diagnostic classification system was used?

- DSM-IV-TR
- DSM-V
- ICD-10
Subsection 1: Administrative Data (Continued)

11. What is the child’s clinical diagnosis? Indicate the diagnostic code and/or diagnosis below.

<table>
<thead>
<tr>
<th>Diagnostic code</th>
<th>Diagnosis name</th>
</tr>
</thead>
<tbody>
<tr>
<td>11a. Primary Diagnosis</td>
<td>______<strong><strong>.</strong></strong> _________________________</td>
</tr>
<tr>
<td>11b. Secondary Diagnosis</td>
<td>______<strong><strong>.</strong></strong> _________________________</td>
</tr>
<tr>
<td>11c. Additional Diagnosis</td>
<td>______<strong><strong>.</strong></strong> _________________________</td>
</tr>
</tbody>
</table>

[IF AN INTERVIEW WAS CONDUCTED, GO TO SUBSECTION 2, FAMILY/LIVING INFORMATION.]

[IF AN INTERVIEW WAS NOT CONDUCTED, DATA COLLECTION IS COMPLETE.]
SUBSECTION 2: FAMILY/LIVING INFORMATION

[READ THE FOLLOWING QUESTIONS TO THE CAREGIVER.]

1. What is your gender?
   - [ ] Male
   - [ ] Female
   - [ ] Transgender
   - [ ] Other (Specify): ________________________________
   - [ ] Declined

2. What is your relationship to (child’s name)?
   - [ ] Birth Parent
   - [ ] Step-Parent
   - [ ] Adoptive Parent
   - [ ] Foster Parent
   - [ ] Grandparent (biological, step, or adoptive)
   - [ ] Sibling (biological, step, or adoptive)
   - [ ] Other Relative (Please specify: ___________________________)
   - [ ] Non-relative not previously listed (e.g., other caregiving adult)
     (Please specify): ___________________________________________
   - [ ] Declined
Subsection 2: Family/Living Information (Continued)

3. Does *(child’s name)* live alone?

- [ ] Yes [GO TO 4]
- [ ] No
- [ ] Declined [GO TO 4]
- [ ] Don’t Know/Information Not Available [GO TO 4]

3a. *(IF NO), with whom does *(child’s name)* live? Please answer yes or no for each of the following. You may say yes to more than one.

<table>
<thead>
<tr>
<th>Relationship</th>
<th>YES</th>
<th>NO</th>
<th>DECLINED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth Mother</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Birth Father</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adoptive Mother</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adoptive Father</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Foster Mother</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Foster Father</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stepmother</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stepfather</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grandmother (Birth, Step, or Adoptive)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grandfather (Birth, Step, or Adoptive)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling(s) (Biological, Step, or Adoptive)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse/Partner</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Youth’s Own Children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other <em>(Please specify)</em></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Subsection 2: Family/Living Information (Continued)

4. Who has legal custody of (child’s name) currently?
   - Two Parents (includes two birth parents, or one birth parent and a step or adoptive parent)
   - Birth Mother Only
   - Birth Father Only
   - Adoptive Parent(s)
   - Sibling(s)
   - Aunt and/or Uncle
   - Grandparent(s)
   - Adult Friend
   - Ward of the State
   - Emancipated
   - Other (Please specify): _______________________________________
   - Declined
   - Don’t Know/Information Not Available

[QUESTIONS 5 AND 6 ARE ONLY ASKED AT BASELINE. IF THIS IS A REASSESSMENT OR DISCHARGE, SKIP TO SUBSECTION 3.]

5. How many children, including (child’s name), are in the household?  |___|___|
   - Declined
   - Don’t Know/Information Not Available

6. What is your family’s annual income?
   - Less than $2,500
   - $2,500 to $4,999
   - $5,000 to $9,999
   - $10,000 to $14,999
   - $15,000 to $24,999
   - $25,000 to $34,999
   - $35,000 to $49,999
   - $50,000 to $74,999
   - $75,000 to $100,000
   - Greater than $100,000
   - Declined
   - Don’t Know/Information Not Available
SUBSECTION 3: THE COLUMBIA IMPAIRMENT SCALE (C.I.S.)
PARENT VERSION

[READ THE BELOW INSTRUCTIONS TO THE CAREGIVER, FOLLOWED BY THE QUESTIONS ON THE NEXT PAGE.]

To help us improve the quality of the treatment that your child receives, we are asking you to complete the following rating scale (C.I.S.). This will help us determine the area or areas in which your child needs help and the progress that your child makes in these areas. It also will give us information that will assist us in making changes in his/her treatment plan to better meet his/her needs.

There are 13 areas of your child’s behavior for you to rate from 0 to 4 with 0 being no problem and 4 being a very bad problem. Using your best judgment, rate each item by indicating the number that best describes your child’s behavior within the past 6 months. You can ask for clarification if you do not understand an item or items.
Subsection 3: CIS – Parent Version (Continued)

**Grantee Staff:** Please circle the number that the caregiver thinks best describes the child’s situation:

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No problem</td>
<td>Very bad problem</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**READ THE FOLLOWING QUESTIONS TO THE CAREGIVER.**

In general, how much of a problem or difficulty do you think [she/he] has with…?

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1)</td>
<td>… getting into trouble?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2)</td>
<td>… getting along with (you/[her/his] mother/mother figure)?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3)</td>
<td>… getting along with (you/[her/his] father/father figure)?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4)</td>
<td>… feeling unhappy or sad?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

How much of a problem or difficulty would you say [she/he] has:

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>5)</td>
<td>… with [her/his] behavior at school (or at [her/his] job)?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6)</td>
<td>… with having fun?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7)</td>
<td>… getting along with adults other than his/her parents (child’s mother and/or father)?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

How much of a problem or difficulty does [she/he] have:

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>8)</td>
<td>… with feeling nervous or afraid?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9)</td>
<td>… getting along with [her/his] sister(s) and/or brother(s)?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10)</td>
<td>… getting along with other kids [her/his] age?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

How much of a problem or difficulty would you say [she/he] has:

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>11)</td>
<td>… getting involved in activities like sports or hobbies?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12)</td>
<td>… with [her/his] school work (doing [her/his] job)?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>13)</td>
<td>… with [her/his] behavior at home?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
**SUBSECTION 4: PEDIATRIC SYMPTOM CHECKLIST – PARENT REPORT (P-PSC-17)**

[READ THE FOLLOWING INSTRUCTIONS AND STATEMENTS TO THE CAREGIVER.]

Emotional health and physical health go together in children. Because parents are often the first to notice a problem with their child’s behavior, emotions, or learning, you may help your child get the best care possible by answering these questions.

Please indicate which statement best describes your child’s behaviors and emotions in the past 6 months.

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Declined</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Fidgety, unable to sit still</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. Feels sad, unhappy</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>3. Daydreams too much</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>4. Refuses to share</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>5. Does not understand other people’s feelings</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>6. Feels hopeless</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>7. Has trouble concentrating</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>8. Fights with other children</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>9. Is down on himself or herself</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>10. Blames others for his or her troubles</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>11. Seems to be having less fun</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>12. Does not listen to rules</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>13. Acts as if driven by motor</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>14. Teases others</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>15. Worries a lot</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>16. Takes things that do not belong to him/her</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>17. Distracted easily</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
</tbody>
</table>

©M.S. Jellinek and J.M. Murphy, Massachusetts General Hospital (http://psc.partners.org)
[THE FOLLOWING THREE QUESTIONS (1–3) ARE ONLY FOR CLIENTS 10 YEARS OF AGE OR OLDER. IF CLIENT IS AGED 9 OR YOUNGER, SKIP TO SUBSECTION 5.]

[QUESTION 1 IS ASKED ONLY AT BASELINE. IF THIS IS A REASSESSMENT OR DISCHARGE INTERVIEW, SKIP TO QUESTION 2.]

This next question is about suicide.

1. Has your child ever tried to kill himself/herself?
   
   □ Yes
   □ No
   □ Declined
   □ Don’t Know/Information Not Available
   □ Not Applicable

[QUESTIONS 2 AND 3 ARE ONLY ASKED AT REASSESSMENT AND DISCHARGE. IF THIS IS A BASELINE INTERVIEW, SKIP TO SUBSECTION 5.]

These next two questions are about suicide.

2. At any time in the past 6 months (including today), did your child seriously think about trying to kill himself/herself?

   □ Yes
   □ No
   □ Declined
   □ Don’t Know/Information Not Available
   □ Not Applicable

3. During the past 6 months (including today), did your child try to kill himself/herself?

   □ Yes
   □ No
   □ Declined
   □ Don’t Know/Information Not Available
   □ Not Applicable
**SUBSECTION 5: Caregiver Strain Questionnaire (CGSQ)**

**[READ THE FOLLOWING INSTRUCTIONS AND QUESTIONS TO THE CAREGIVER.]**

Please think back over the past 6 months and try to remember how things have been for your family. We are trying to get a picture of how life has been in your household over that time. For each question, please tell me which response (which number) fits best.

In the past 6 months, how much of a challenge was the following:

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little</th>
<th>Some-what</th>
<th>Quite a bit</th>
<th>Very much</th>
<th>Declined</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Interruption of personal time resulting from your child's emotional or behavioral challenges?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. Your missing work or neglecting other duties because of your child's emotional or behavioral challenges?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. Disruption of family routines due to your child's emotional or behavioral challenges?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. Any family member having to do without things because of your child's emotional or behavioral challenges?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5. Financial strain for your family as a result of your child's emotional or behavioral challenges?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>6. Disruption or upset of relationships within the family due to your child's emotional or behavioral challenges?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Subsection 5: CGSQ (Continued)

In this section, please continue to look back and try to remember how you have felt during the past 6 months.

For each question, please tell me which response fits best.

In the past 6 months:

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
<th>Declined</th>
</tr>
</thead>
<tbody>
<tr>
<td>7. How sad or unhappy did you feel as a result of your child's emotional or behavioral challenges?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>8. How embarrassed did you feel about your child's emotional or behavioral challenges?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>9. How angry did you feel toward your child?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>10. How worried did you feel about your child's future?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>11. How worried did you feel about your family's future?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>12. How guilty did you feel about your child's emotional or behavioral challenges?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>13. How resentful did you feel toward your child?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
End of Instrument:

Thank you for participating in the child and family outcomes portion of the National System of Care Expansion Evaluation.
Appendix B

Child/Youth Tools
Public Burden Statement: An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. The OMB control number for this project is 0930-0349. Public reporting burden for this collection of information is estimated to average 23 minutes per respondent, per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to SAMHSA Reports Clearance Officer, 5600 Fishers Lane, Room 15E57-B, Rockville, Maryland, 20857.
Thank you for your willingness to participate in the Child and Family Outcomes Survey. The purpose of this survey is to assess changes in the mental health and well-being of children and their families while they are participating and receiving services from the Systems of Care.

Your responses to these questions will be kept confidential and will not be shared outside of the evaluation team. In any of our reports, your responses will be combined with other people’s responses, so your answers will never be attributed to your name. Please sign the consent/assent form prior to completing this questionnaire.
CHILD/YOUTH VERSION

INSTRUCTIONS

This version will be administered directly to children/youth ages 11 to 17 at baseline/entry into services and at 6 and 12 months or at discharge. This version includes the following:

1. Subsection 1: Administrative Data
2. Subsection 2: Family/Living Information (intentionally missing)
4. Subsection 4: Pediatric Symptom Checklist-17 – self report
5. Subsection 5: Caregiver Strain Questionnaire (intentionally missing)

There are two components of this instrument. Subsection 1 is answered by staff using information from administrative and clinical records. Subsections 3-4 are to be administered verbally to the youth by local systems staff.
RECORD MANAGEMENT

[RECORD MANAGEMENT IS REPORTED BY GRANTEE STAFF AT BASELINE, REASSESSMENT, AND DISCHARGE REGARDLESS OF WHETHER AN INTERVIEW IS CONDUCTED.]

Consumer ID  ____________________________

Grant ID (Grant/Contract/Cooperative Agreement)  ____________________________

1. Indicate Assessment Type:

- [ ] Baseline
- [ ] Reassessment
- [ ] Clinical Discharge

[ENTER THE MONTH AND YEAR WHEN THE CONSUMER FIRST RECEIVED SERVICES UNDER THE GRANT FOR THIS EPISODE OF CARE.]

<table>
<thead>
<tr>
<th>MONTH</th>
<th>YEAR</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Which reassessment?

[ENTER 06 FOR A 6–MONTH AND 12 FOR A 12–MONTH.]

2. Was the interview conducted?

- [ ] Yes
- [ ] No

When?

<table>
<thead>
<tr>
<th>MONTH</th>
<th>DAY</th>
<th>YEAR</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Why not? Choose only one.

- [ ] Not able to obtain consent from proxy
- [ ] Consumer was impaired or unable to provide consent
- [ ] Consumer refused this interview only
- [ ] Consumer was not reached for interview
- [ ] Consumer refused all interviews
SUBSECTION 1: ADMINISTRATIVE DATA

[SUBSECTION 1 IS COMPILED BY GRANTEE STAFF FROM RECORDS.]

1. Is the child/youth enrolled in the CMHI Outcome Evaluation?
   - [ ] Yes [IF THIS IS A BASELINE, GO TO SUBSECTION 1, QUESTION 2. OTHERWISE SKIP TO SUBSECTION 1, QUESTION 6.]
   - [ ] No [STOP HERE.]

2. What is the date of the child/youth’s...
   2a. First assessment for the system of care?
       [___|___| / |___|___| / |___|___|___|___|
       Month     Day     Year
   2b. First service (after assessment) received through the system of care?
       [___|___| / |___|___| / |___|___|___|___|
       Month     Day     Year
   2c. Most recent service planning team meeting in the system of care?
       [___|___| / |___|___| / |___|___|___|___|
       Month     Day     Year
Subsection 1: Administrative Data (Continued)

3. **Who participated in the development of the child/youth’s service plan?** [Select all that apply and specify role as noted.]
   - Child/youth’s caregiver or guardian
   - Child/youth
   - Other family member
   - Case manager/service coordinator
   - Wraparound facilitator (if not case manager/service coordinator)
   - Therapist
   - Other mental health staff (e.g., behavioral aide, respite worker) *(Specify role: __________________)*
   - Intellectual disabilities provider
   - Family advocate
   - Parent/Peer support provider
   - Youth advocate
   - Youth/Peer support provider
   - Education staff (e.g., teacher, counselor) *(Specify role: __________________)*
   - Child welfare staff (e.g., case worker) *(Specify role: __________________)*
   - Juvenile justice staff (e.g., probation officer) *(Specify role: __________________)*
   - Physical health staff (e.g., pediatrician, nurse) *(Specify role: __________________)*
   - Other *(For up to three people) (Specify role: __________________)*
          *(Specify role: __________________)*
          *(Specify role: __________________)*

4. **Which agency or individual referred the child/youth to the program?**
   - Mental Health Agency/Clinic/Provider
   - Physical Health Care Agency/Clinic/Provider
   - Substance Abuse Agency/Clinic/Provider
   - Intellectual Disabilities Agency/Clinic/Provider
   - School/Educational Facility/Staff
   - Early Intervention
   - Child Welfare/Child Protective Services
   - Family Court
   - Juvenile Court/Corrections/Probation/Police
   - Caregiver
   - Child/Youth referred himself or herself
   - Other *(Please specify: __________________)*
Subsection 1: Administrative Data (Continued)

5. **What led to the child/youth being referred for services? [Select all that apply.]**

- Conduct/delinquency behaviors (including physical aggression, extreme verbal abuse, non-compliance, sexual acting out, property damage, theft, running away, sexual assault, fire setting, cruelty to animals, truancy, police contact)
- Intellectual disabilities
- Hyperactive and attention-related behaviors (including hyperactive, impulsive, attentional difficulties)
- School/Educational performance
- Depression (including major depression, dysthymia, sleep disorders, somatic complaints)
- Anxiety (including fears and phobias, generalized anxiety, social avoidance, obsessive-compulsive behavior, post-traumatic stress disorder)
- Adjustment-related issues (including changes in behaviors or emotions in reaction to a significant life stress)
- Suicide-related thoughts or actions (including suicide ideation or suicide attempt)
- Self-Injury (self-injurious behavior, hair pulling, cutting, etc.)
- Psychotic behaviors (including hallucinations, delusions, strange or odd behaviors)
- Substance use, abuse, and drug dependency behaviors
- Learning disabilities
- Eating disorders (including anorexia, bulimia)
- Sleeping problems
- Current home unable to meet child/youth’s needs
- Maltreatment (child abuse and neglect)
- Behavioral concerns (including aggression, severe defiance, acting out, impulsivity, recklessness, and excessive level of overactivity)
- Excessive crying/tantrums
- Persistent noncompliance (when directed by caregivers/adults)
- Pervasive developmental disabilities (including autistic behaviors, extreme social avoidance, stereotypes, perseverative behavior)
- Specific developmental disabilities (including enuresis, encopresis, expressive or receptive speech and language delay)
- Separation problems
- Feeding problems (including failure to thrive)
- Excluded from preschool or childcare due to behavioral or developmental problems
- Attachment problems
- Other concerns/issues that are related to child/youth’s health (cancer, illness, or disease related-problems)
- Other (Please specify: ________________________________)

6. **With which of the following agencies is the child/youth involved? [Select all that apply.]**

- Mental Health Agency/Clinic/Provider
- Physical Health Care Agency/Clinic/Provider
- Substance Abuse Agency/Clinic/Provider
- Intellectual Disabilities Agency/Clinic/Provider
- School/Educational Facility
- Early Intervention
- Child Welfare/Child Protective Services
- Family Court
- Juvenile Court/Corrections/Probation/Police
- Other (Please specify: ________________________________)

Child/Youth Tools
Subsection 1: Administrative Data (Continued)

7. During the past 6 months, was the child/youth insured through...? [Select all that apply.]
   - Medicaid
   - CHIP
   - SSI
   - Private Insurance
   - Other (Please specify: _____________________________)
   - No insurance

8. What is the census block group of the address where the child/youth currently lives?
   __________________________

   Please note: To obtain the census block group of the consumer, you will need the consumer’s address. This should be obtained from consumer records. The address must be entered into the system to generate the census block; however, the system will not save the address of the consumer, only the census block group.

9. What is the date of the child/youth’s most recent diagnostic evaluation?
   _______ / _______ / _______
   Month     Day    Year

10. Which diagnostic classification system was used?
    - DSM-IV-TR
    - DSM-V
    - ICD-10

11. What is the child/youth’s clinical diagnosis? Indicate the diagnostic code and/or diagnosis below.
    
    | Diagnostic code | Diagnosis name |
    |-----------------|----------------|
    | 11a. Primary Diagnosis | _______.____ | _____________________________ |
    | 11b. Secondary Diagnosis | _______.____ | _____________________________ |
    | 11c. Additional Diagnosis | _______.____ | _____________________________ |

[IF AN INTERVIEW WAS CONDUCTED, GO TO SUBSECTION 3, COLUMBIA IMPAIRMENT SCALE.]

[IF AN INTERVIEW WAS NOT CONDUCTED, DATA COLLECTION IS COMPLETE.]
[SUBSECTION 2 DOES NOT APPLY TO THE CHILD/YOUTH TOOL. GO TO SUBSECTION 3, COLUMBIA IMPAIRMENT SCALE.]
[READ THE BELOW INSTRUCTIONS TO THE CHILD/YOUTH, FOLLOWED BY THE QUESTIONS ON THE NEXT PAGE.]

All of the remaining questions I will ask you today will focus on events in the past 6 months.

To help us improve the quality of the treatment that you receive, we are asking you to complete the following rating scale (C.I.S.). This will help us determine the area or areas in which you need help and the progress that you make in these areas. It also will give us information that will assist us in making changes in your treatment plan to better meet your needs.

There are 13 areas of your behavior for you to rate from 0 to 4 with 0 being no problem for you, and 4 being a very bad problem. After I read each question, tell me the number that best describes your behavior within the past 6 months. You can ask me for help if you don’t understand a question.
Subsection 3: CIS – Youth Version (Continued)

**Grantee Staff:** Please circle the number that the child or youth thinks best describes his or her situation:

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No problem</td>
<td>Very bad problem</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**[READ THE FOLLOWING QUESTIONS TO THE CHILD/YOUTH.]**

In general, how much of a problem or difficulty do you think you have with:

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>DECLINED</th>
</tr>
</thead>
<tbody>
<tr>
<td>1)</td>
<td>… getting into trouble?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2)</td>
<td>… getting along with your mother/mother figure?</td>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
<td>DECLINED</td>
</tr>
<tr>
<td>3)</td>
<td>… getting along with your father/father figure?</td>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
<td>DECLINED</td>
</tr>
<tr>
<td>4)</td>
<td>… feeling unhappy or sad?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How much of a problem or difficulty would you say you have:

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>N/A</th>
<th>DECLINED</th>
</tr>
</thead>
<tbody>
<tr>
<td>5)</td>
<td>… with your behavior at school (or at your job)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6)</td>
<td>… with having fun?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7)</td>
<td>… getting along with adults other than your mother and/or your father?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How much of a problem or difficulty do you have:

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>DECLINED</th>
</tr>
</thead>
<tbody>
<tr>
<td>8)</td>
<td>… with feeling nervous or afraid?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9)</td>
<td>… getting along with your sister(s) and/or brother(s)?</td>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
<td>DECLINED</td>
</tr>
<tr>
<td>10)</td>
<td>… getting along with other kids your age?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

How much of a problem or difficulty would you say you have:

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>DECLINED</th>
</tr>
</thead>
<tbody>
<tr>
<td>11)</td>
<td>… getting involved in activities like sports or hobbies?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12)</td>
<td>… with your school work (doing your job)?</td>
<td></td>
<td></td>
<td></td>
<td>N/A</td>
<td>DECLINED</td>
</tr>
<tr>
<td>13)</td>
<td>… with your behavior at home?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Please indicate which statement best describes your behavior and emotions in the past 6 months.

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Declined</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Fidgety, unable to sit still</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Feel sad, unhappy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Daydream too much</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Refuse to share</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Do not understand other people’s feelings</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Feel hopeless</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Have trouble concentrating</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Fight with other children</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Down on yourself</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Blame others for your troubles</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Seem to be having less fun</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Do not listen to rules</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Act as if driven by motor</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Tease others</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Worry a lot</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Take things that do not belong to you</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Distract easily</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
SUBSECTION 5: Caregiver Strain Questionnaire (CGSQ)

[SUBSECTION 5 DOES NOT APPLY TO THE CHILD/YOUTH TOOL. DATA COLLECTION IS COMPLETE.]

End of Instrument:

Thank you for participating in the Child and Family Outcomes portion of the National System of Care Expansion Evaluation.
Appendix C

Young Adult Tools
Public Burden Statement: An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. The OMB control number for this project is 0930-0349. Public reporting burden for this collection of information is estimated to average 23 minutes per respondent, per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to SAMHSA Reports Clearance Officer, 5600 Fishers Lane, Room 15E57-B, Rockville, Maryland, 20857.
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Your responses to these questions will be kept confidential and will not be shared outside of the evaluation team. In any of our reports, your responses will be combined with other people’s responses, so your answers will never be attributed to your name. Please sign the consent form prior to completing this questionnaire.
YOUNG ADULT VERSION

INSTRUCTIONS

This version will be administered directly to young adults ages 18 and up at baseline/entry into services and at 6 and 12 months or at discharge. This version includes the following:

1. Subsection 1: Administrative Data
2. Subsection 2: Family/Living Information – self report
4. Subsection 4: Pediatric Symptom Checklist-17 – self report
5. Subsection 5: Caregiver Strain Questionnaire (intentionally missing)

There are two components of this instrument. Subsection 1 is answered by staff using information from administrative and clinical records. Subsections 2-4 are to be administered verbally to the young adult by local systems staff.
RECORD MANAGEMENT

[RECORD MANAGEMENT IS REPORTED BY GRANTEE STAFF AT BASELINE, REASSESSMENT, AND DISCHARGE REGARDLESS OF WHETHER AN INTERVIEW IS CONDUCTED.]

Consumer ID  ________________

Grant ID (Grant/Contract/Cooperative Agreement)  ________________

1. Indicate Assessment Type:

|   |   |   |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|---|---|
|   |   |   |   |   |   |   |   |   |   |

- Baseline
  - [ENTER THE MONTH AND YEAR WHEN THE CONSUMER FIRST RECEIVED SERVICES UNDER THE GRANT FOR THIS EPISODE OF CARE.]
  - ______/______/______

- Reassessment
  - Which reassessment?
  - ______
  - [ENTER 06 FOR A 6-MONTH AND 12 FOR A 12-MONTH.]

- Clinical Discharge

2. Was the interview conducted?

|   |   |   |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|---|---|
|   |   |   |   |   |   |   |   |   |   |

- Yes

- No
  - Why not? Choose only one.
    - Not able to obtain consent from proxy
    - Consumer was impaired or unable to provide consent
    - Consumer refused this interview only
    - Consumer was not reached for interview
    - Consumer refused all interviews
Young Adult Tools C-5

SUBSECTION 1: ADMINISTRATIVE DATA

[SUBSECTION 1 IS COMPILED BY GRANTEE STAFF FROM RECORDS.]

1. Is the young adult enrolled in the CMHI Outcome Evaluation?
   - Yes [IF THIS IS A BASELINE, GO TO SUBSECTION 1, QUESTION 2. OTHERWISE SKIP TO SUBSECTION 1, QUESTION 6.]
   - No [STOP HERE.]

2. What is the date of the young adult’s…
   2a. First assessment for the system of care?
      | | / | | | |
      Month Day Year
   2b. First service (after assessment) received through the system of care?
      | | / | | | |
      Month Day Year
   2c. Most recent service planning team meeting in the system of care?
      | | / | | | |
      Month Day Year
Subsection 1: Administrative Data (Continued)

3. **Who participated in the development of the young adult’s service plan? [Select all that apply and specify role as noted.]**

- [ ] Young adult’s caregiver or guardian
- [ ] Young adult
- [ ] Other family member
- [ ] Case manager/service coordinator
- [ ] Wraparound facilitator (if not case manager/service coordinator)
- [ ] Therapist
- [ ] Other mental health staff (e.g., behavioral aide, respite worker) *(Specify role: ___________________)*
- [ ] Intellectual disabilities provider
- [ ] Family advocate
- [ ] Parent/Peer support provider
- [ ] Youth advocate
- [ ] Youth/Peer support provider
- [ ] Education staff (e.g., teacher, counselor) *(Specify role: ___________________)*
- [ ] Child welfare staff (e.g., case worker) *(Specify role: ___________________)*
- [ ] Juvenile justice staff (e.g., probation officer) *(Specify role: ___________________)*
- [ ] Physical health staff (e.g., pediatrician, nurse) *(Specify role: ___________________)*
- [ ] Other *(For up to three people) *(Specify role: ___________________)*
  *(Specify role: ___________________)*
  *(Specify role: ___________________)*

4. **Which agency or individual referred the young adult to the program?**

- [ ] Mental Health Agency/Clinic/Provider
- [ ] Physical Health Care Agency/Clinic/Provider
- [ ] Substance Abuse Agency/Clinic/Provider
- [ ] Intellectual Disabilities Agency/Clinic/Provider
- [ ] School/Educational Facility/Staff
- [ ] Early Intervention
- [ ] Child Welfare/Child Protective Services
- [ ] Family Court
- [ ] Juvenile Court/Corrections/Probation/Police
- [ ] Caregiver
- [ ] Young adult referred himself or herself
- [ ] Other *(Please specify: ___________________)*
Subsection 1: Administrative Data (Continued)

5. **What led to the young adult being referred for services? [Select all that apply.]**

- [ ] Conduct/delinquency-related behaviors (including physical aggression, extreme verbal abuse, non-compliance, sexual acting out, property damage, theft, running away, sexual assault, fire setting, cruelty to animals, truancy, police contact)
- [ ] Intellectual disabilities
- [ ] Hyperactive and attention-related behaviors (including hyperactive, impulsive, attentional difficulties)
- [ ] School/Educational performance
- [ ] Depression (including major depression, dysthymia, sleep disorders, somatic complaints)
- [ ] Anxiety (including fears and phobias, generalized anxiety, social avoidance, obsessive-compulsive behavior, post-traumatic stress disorder)
- [ ] Adjustment-related issues (including changes in behaviors or emotions in reaction to a significant life stress)
- [ ] Suicide-related thoughts or actions (including suicide ideation or suicide attempt)
- [ ] Self-Injury (self-injurious behavior, hair pulling, cutting, etc.)
- [ ] Psychotic behaviors (including hallucinations, delusions, strange or odd behaviors)
- [ ] Substance use, abuse, and drug dependency behaviors
- [ ] Learning disabilities
- [ ] Eating disorders (including anorexia, bulimia)
- [ ] Sleeping problems
- [ ] Current home unable to meet young adult’s needs
- [ ] Maltreatment (child abuse and neglect)
- [ ] Behavioral concerns (including aggression, severe defiance, acting out, impulsivity, recklessness, and excessive level of overactivity)
- [ ] Persistent noncompliance (when directed by caregivers/adults)
- [ ] Pervasive developmental disabilities (including autistic behaviors, extreme social avoidance, stereotypes, perseverative behavior)
- [ ] Other concerns/issues that are related to young adult’s health (cancer, illness, or disease related-problems)
- [ ] Other (Please specify: _________________________________)

6. **With which of the following agencies is the young adult involved? [Select all that apply.]**

- [ ] Mental Health Agency/Clinic/Provider
- [ ] Physical Health Care Agency/Clinic/Provider
- [ ] Substance Abuse Agency/Clinic/Provider
- [ ] Intellectual Disabilities Agency/Clinic/Provider
- [ ] School/Educational Facility
- [ ] Early Intervention
- [ ] Child Welfare/Child Protective Services
- [ ] Family Court
- [ ] Juvenile Court/Corrections/Probation/Police
- [ ] Other (Please specify: _________________________________)
Subsection 1: Administrative Data (Continued)

7. What is the census block group of the address where the young adult currently lives?
   ____________________

   Please note: To obtain the census block group of the consumer, you will need the consumer’s address. This should be obtained from consumer records. The address must be entered into the system to generate the census block; however, the system will not save the address of the consumer, only the census block group.

8. During the past 6 months, was the young adult insured through...? [Select all that apply.]
   - Medicaid
   - CHIP
   - SSI
   - Private Insurance
   - Other (Please specify: _____________________________)
   - No insurance

9. What was the date of the young adult’s most recent diagnostic evaluation?
   |___|___| / |___|___| / |___|___|___|___|
   Month Day Year

10. Which diagnostic classification system was used?
    - DSM-IV-TR
    - DSM-V
    - ICD-10

11. What is the young adult’s clinical diagnosis? Indicate the diagnostic code and/or diagnosis below.
    Diagnostic code  Diagnosis name
    11a. Primary Diagnosis  _______:____  ____________________________
    11b. Secondary Diagnosis  _______:____  ____________________________
    11c. Additional Diagnosis  _______:____  ____________________________

[IF AN INTERVIEW WAS CONDUCTED, GO TO SUBSECTION 2, FAMILY/LIVING INFORMATION.]
[IF AN INTERVIEW WAS NOT CONDUCTED, DATA COLLECTION IS COMPLETE.]
SUBSECTION 2: FAMILY/LIVING INFORMATION

[READ THE FOLLOWING QUESTIONS TO THE YOUNG ADULT.]

[QUESTIONS 1 AND 2 DO NOT APPLY TO THE YOUNG ADULT TOOL AND HAVE BEEN OMITTED.]

3. Do you live alone?

☐ Yes [GO TO 6]
☐ No
☐ Declined [GO TO 6]
☐ Don’t Know/Information Not Available [GO TO 6]

3a. [IF NO], with whom do you live? Please answer yes or no for each of the following. You may say yes to more than one.

<table>
<thead>
<tr>
<th>Relationship</th>
<th>YES</th>
<th>NO</th>
<th>DECLINED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth Mother</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Birth Father</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adoptive Mother</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adoptive Father</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Foster Mother</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Foster Father</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stepmother</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stepmother</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grandmother (Biological, Step, or Adoptive)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grandfather (Biological, Step, or Adoptive)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling(s) (Biological, Step, or Adoptive)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse/Partner</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Youth’s Own Children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (Please specify)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
6. What is your family’s annual income?

- Less than $2,500
- $2,500 to $4,999
- $5,000 to $9,999
- $10,000 to $14,999
- $15,000 to $24,999
- $25,000 to $34,999
- $35,000 to $49,999
- $50,000 to $74,999
- $75,000 to $100,000
- Greater than $100,000
- Declined
- Don’t Know/Information Not Available

7. Are you currently enrolled in school or a job training program? [IF ENROLLED] Is that full time or part time?

- Not enrolled
- Enrolled, full time
- Enrolled, part time
- Other (Specify) ___________________________
- Declined
- Don’t Know/Information Not Available

8. What is the highest level of education you have finished, whether or not you received a degree?

- Less than 12th grade
- 12th grade/high school diploma/equivalent (GED)
- Voc/tech diploma
- Some college or university
- Bachelor’s degree (BA, BS)
- Graduate work/graduate degree
- Declined
- Don’t Know/Information Not Available
Subsection 2: Family/Living Information (Continued)

9. Are you currently employed?

[CLARIFY BY FOCUSING ON STATUS DURING MOST OF THE PREVIOUS WEEK, DETERMINING WHETHER CONSUMER WORKED AT ALL OR HAD A REGULAR JOB BUT WAS OFF WORK.]

- Employed full time (35+ hours per week, or would have been)
- Employed part time
- Unemployed, looking for work
- Unemployed, disabled
- Unemployed, volunteer work
- Unemployed, retired
- Unemployed, not looking for work
- Other (Specify) ___________________________
- Declined
- Don’t Know/Information Not Available

9a. [IF EMPLOYED]

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Declined</th>
<th>Don’t Know/Information Not Available</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are you paid at or above the minimum wage?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are your wages paid directly to you by your employer?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Could anyone have applied for this job?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

[QUESTIONS 10 AND 11 ARE ONLY ASKED AT BASELINE. IF THIS IS NOT A BASELINE, SKIP TO QUESTION 12.]

10. Have you ever experienced violence or trauma in any setting (including community or school violence; domestic violence; physical, psychological, or sexual maltreatment/assault within or outside of the family; natural disaster; terrorism; neglect; or traumatic grief)?

- Yes
- No [GO TO 12]
- Refused [GO TO 12]
- Don’t Know/Information Not Available [GO TO 12]

1 For information on the Federal minimum wage, go to http://www.dol.gov/dol/topic/wages.
## Subsection 2: Family/Living Information (Continued)

11. Did any of these experiences feel so frightening, horrible, or upsetting that in the past and/or the present you:

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Declined</th>
<th>Don't Know/Information Not Available</th>
</tr>
</thead>
<tbody>
<tr>
<td>11a. Have had nightmares about it or thought about it when you did not want to?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11b. Tried hard not to think about it or went out of your way to avoid situations that remind you of it?</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>11c. Were constantly on guard, watchful, or easily startled?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11d. Felt numb and detached from others, activities, or your surroundings?</td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

12. In the past 30 days, how often have you been hit, kicked, slapped, or otherwise physically hurt?

- Never
- Once
- A few times
- More than a few times
- Declined
- Don't Know/Information Not Available
SUBSECTION 3: THE COLUMBIA IMPAIRMENT SCALE (C.I.S.)
YOUTH VERSION

[READ THE BELOW INSTRUCTIONS TO THE YOUNG ADULT, FOLLOWED BY THE QUESTIONS ON THE NEXT PAGE.]

All of the remaining questions I will ask you today will focus on events in the past 6 months.

To help us improve the quality of the treatment that you receive, we are asking you to complete the following rating scale (C.I.S.). This will help us determine the area or areas in which you need help and the progress that you make in these areas. It also will give us information that will assist us in making changes in your treatment plan to better meet your needs.

There are 13 areas of behavior for you to rate from 0 to 4 with 0 being no problem for you, and 4 being a very bad problem. Rate each item by indicating the number that best describes your behavior within the past 6 months. You can ask for clarification if you do not understand an item or items.
**Subsection 3: CIS – Youth Version (Continued)**

**Grantee Staff:** Please circle the number that the young adult thinks best describes his or her situation:

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>No problem</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Very bad problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**[READ THE FOLLOWING QUESTIONS TO THE YOUNG ADULT.]**

In general, how much of a problem or difficulty do you think you have with…?

| 1) ... getting into trouble? | 0 | 1 | 2 | 3 | 4 | DECLINED |
| 2) ... getting along with your mother/mother figure? | 0 | 1 | 2 | 3 | 4 | N/A | DECLINED |
| 3) ... getting along with your father/father figure? | 0 | 1 | 2 | 3 | 4 | N/A | DECLINED |
| 4) ... feeling unhappy or sad? | 0 | 1 | 2 | 3 | 4 | DECLINED |

How much of a problem or difficulty would you say you have:

| 5) ... with your behavior at school (or at your job)? | 0 | 1 | 2 | 3 | 4 | N/A | DECLINED |
| 6) ... with having fun? | 0 | 1 | 2 | 3 | 4 | DECLINED |
| 7) ... getting along with adults other than (your mother and/or father)? | 0 | 1 | 2 | 3 | 4 | DECLINED |

How much of a problem or difficulty do you have:

| 8) ... with feeling nervous or afraid? | 0 | 1 | 2 | 3 | 4 | DECLINED |
| 9) ... getting along with your sister(s) and/or brother(s)? | 0 | 1 | 2 | 3 | 4 | N/A | DECLINED |
| 10) ... getting along with other people your age? | 0 | 1 | 2 | 3 | 4 | DECLINED |

How much of a problem or difficulty would you say you have:

| 11) ... getting involved in activities like sports or hobbies? | 0 | 1 | 2 | 3 | 4 | DECLINED |
| 12) ... with your school work (doing your job)? | 0 | 1 | 2 | 3 | 4 | N/A | DECLINED |
| 13) ... with your behavior at home? | 0 | 1 | 2 | 3 | 4 | DECLINED |
**SUBSECTION 4: PEDIATRIC SYMPTOM CHECKLIST – YOUTH REPORT (Y-PSC-17)**

*[READ THE FOLLOWING STATEMENT TO THE YOUNG ADULT.]*

Please indicate which statement best describes your behaviors and emotions in the past 6 months.

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Declined</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Fidgety, unable to sit still</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Feel sad, unhappy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Daydream too much</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Refuse to share</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Do not understand other people’s feelings</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Feel hopeless</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Have trouble concentrating</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Fight with other children</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>9. Down on yourself</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Blame others for your troubles</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Seem to be having less fun</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Do not listen to rules</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Act as if driven by motor</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Tease others</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Worry a lot</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Take things that do not belong to you</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Distract easily</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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QUESTION 1 IS ONLY ASKED AT BASELINE. IF THIS IS A REASSESSMENT OR DISCHARGE INTERVIEW, SKIP TO QUESTION 2.

This next question is about suicide.

1. Have you ever tried to kill yourself?
   - Yes
   - No
   - Declined
   - Don’t Know/Information Not Available
   - Not Applicable

[QUESTIONS 2 AND 3 ARE ONLY ASKED AT REASSESSMENT AND DISCHARGE. IF THIS IS A BASELINE INTERVIEW, DATA COLLECTION IS COMPLETE.]

These next two questions are about suicide.

2. At any time in the past 6 months (including today), did you seriously think about trying to kill yourself?
   - Yes
   - No
   - Declined
   - Don’t Know/Information Not Available
   - Not Applicable

3. During the past 6 months (including today), did you try to kill yourself?
   - Yes
   - No
   - Declined
   - Don’t Know/Information Not Available
   - Not Applicable
SUBSECTION 5: Caregiver Strain Questionnaire (CGSQ)

SUBSECTION 5 DOES NOT APPLY TO THE YOUNG ADULT TOOL. DATA COLLECTION IS COMPLETE.

End of Instrument:

Thank you for participating in the Child and Family Outcomes portion of the National System of Care Expansion Evaluation.
Appendix D

Sample Consent/Assent Forms
CMHI SOC Evaluation: Child and Family Outcomes

Sample Assent – Youth (Ages 11-17)
Sample Assent – Youth (Ages 11-17)

Purpose

You have been asked to participate in the Child and Family Outcomes Survey because you are receiving services through (system of care name). We would like to ask you some questions about yourself, and what you think about the services you receive. We want to find out if the services you receive help you. If they do, they may also help other children and their families.

Sponsor

This project is sponsored by the Substance Abuse and Mental Health Services Administration (SAMHSA). SAMHSA wants to know more about these services and to help improve them.

What you will be asked to do

Participation in this survey is voluntary. You will be asked to participate in up to three interviews: when you first come in, 6 months after that, and 12 months after that or at your last visit. The interviews will take approximately 25 minutes. Data will be collected by (system of care name) staff through interviews with you, your parent/caregiver, and from your case file. You will be asked these questions as part of your regular visit. There are no right or wrong answers to the survey questions.

Questions of a Sensitive Nature

You will be asked questions about how you feel about various things such as, your behavior and things you do at home, in school, and in your neighborhood. You will be asked about what activities you do with your family and friends. You will be asked about the services you have received. If some of the questions make you feel upset or sad, please let the person interviewing you know and the interview will be ended.

Risks

There are very few risks to being in this study. You may feel uncomfortable about answering questions about yourself. Please inform your interviewer if you are uncomfortable, and the interviewer will work with you in deciding if you want to continue or not.

Benefits

There are no direct benefits to this study. The ultimate goal of the survey is to improve the lives of children and young adults who receive these services and their families, by improving upon the services provided.
Confidentiality

The information you share with us will only be used for the purposes of this evaluation. Papers with your name on them will be kept in a locked filing cabinet. Only limited project staff will have access to you data. We will keep your information private to the extent permitted by law. If you report any intent to harm yourself or someone else, we will report it to the proper authorities.

Your interview will always take place in private. We will not use any information that identifies you or your family in any reports we write. Neither your health care nor your health insurance coverage will be affected by anything you say in this session. We have already asked your parent or guardian for permission to interview you.

Contact Information

If you have any questions about this project, you may call SAMHSA’s Project Officer for this evaluation, Dr. Kirstin Painter, at 240-276-1932.

If you have any questions about your rights and welfare as a research participant, you may contact [insert name of grantee IRB representative] at [insert contact phone of grantee IRB representative].

Voluntary Agreement to Participate

Rights Regarding Decision to Participate: I understand that I will not be in trouble if I do not want to be in the survey or if I decide to quit later. I do not have to answer questions that I do not want to answer. If I change my mind and quit, all of my answers to questions will be destroyed, if that is what I want. No one will say that I cannot be in other studies because I do not want to be in this study. No one can say that I cannot get services because I do not want to be in this study.

I have read this form or it has been read to me. I understand what it says. My questions (if any) have been answered. A copy of this form will be given to me. By signing my name below, I freely agree to participate in this survey.

Name (Type or Print Full Name): ________________________________

Signature: ________________________________

Date: ___/___/____
CMHI SOC Evaluation: Child and Family Outcomes

Sample Informed Consent – Young Adult (Ages 18-21)
Sample Informed Consent – Young Adult Version (Ages 18-21)

Purpose

The Substance Abuse and Mental Health Services Administration (SAMHSA) in the United States Department of Health and Human Services is sponsoring an evaluation of children’s mental health services and systems of care. A system of care is a coordinated network of community-based services and supports that are organized to meet the challenges that children and youth with serious mental health needs and their families. You were invited to participate in this study because you currently receive or have received such services in the past. The purpose of this interview is to find out the ways in which youth are involved in their system of care. In this study, we will ask you about your behaviors and emotions, what activities you do at home, in school, and around your neighborhood, the types of services you receive, and how you feel about these services. The results of the project will be used to help improve services for children, young adults, and their families.

Description of Participation

Participation in this survey is completely voluntary. You will be asked to participate in up to three interviews: an interview at intake, 6 months, and 12 months or at discharge if you are enrolled in the program for less than 12 months. The Evaluation interview will take about 25 minutes. Data will be collected by (system of care name) staff through interviews with you and use of some routinely collected information from your records. You will be asked these questions as part of your regular visit. There are no right or wrong answers to the questions. You may stop the interview at any time for any reason. You may also choose to skip any of the questions.

The Evaluation interview will take about 11 minutes. Data will be collected by (system of care name) personnel through a combination of interviews with you and abstraction of routinely collected clinical information from client records. You will be asked these questions as part of your regular visit.

Risk

You may feel uncomfortable about answering some questions about your experiences. You will be able to inform the interviewer if you are uncomfortable, and s/he will work with you to decide if you would like to continue with the interview or not.

Benefits

You will not get any direct benefit from being interviewed. However, the information you provides may help improve the services offered to children, young adults, and their families.
Confidentiality

The information you share with us will only be used for the purposes of this study. We will keep your information private to the extent permitted by law. If you report any intent to harm yourself or someone else, we will report it to the proper authorities.

Your health care services or insurance coverage will not be affected by anything you say during the interview. We will record the interview to help us with our notes. The session recordings will be stored in a secure network folder and will be destroyed at the end of the project. The recording will be reviewed only by a few evaluation team members. Your name will not be used in any reports we write. This signed consent form and any forms and records from the study will be kept in a secure place that only project staff will be able to access.

Contact Information

If you have any questions about this project, you may call SAMHSA’s Project Officer for this evaluation, Dr. Kirstin Painter, at 240-276-1932.

If you have any questions about your rights and welfare as a research participant, you may contact [insert name of grantee IRB representative] at [insert contact phone of grantee IRB representative].

Voluntary Consent

Rights Regarding Decision to Participate: I understand that I will not be in trouble if I do not want to be in the survey or if I decide to quit later. I do not have to answer questions that I do not want to answer. If I change my mind and quit, all of my answers to questions will be destroyed, if that is what I want. No one will say that I cannot be in other projects because I do not want to be in this project. No one can say that I cannot get services because I do not want to be in this project.

I read this form or it has been read to me. I understand what it says. My questions (if any) have been answered. A copy of this form will be given to me. By signing my name below, I freely agree to be in the project.

Young Adult’s Printed Name: _____________________________________________
Young Adult’s Signature: ________________________________________________
Date: ___/___/______
CMHI SOC Evaluation: Child and Family Outcomes

Sample Informed Consent – Caregiver (Parent, Guardian, Primary Caregiver)
Sample Informed Consent – Caregiver (Parent, Guardian, Primary Caregiver)

Purpose

The Substance Abuse and Mental Health Services Administration (SAMHSA) in the United States Department of Health and Human Services is sponsoring an evaluation of children’s mental health services and systems of care. A system of care is a coordinated network of community-based services and supports that are organized to meet the challenges that children and youth with serious mental health needs and their families face. These systems of care are funded to improve services for children and families. (The system of care name) where your child has received services is a part of this study. The purpose of this interview is to find out the ways in which children and youth are involved in their systems of care. In this study, we will ask you about you and your child’s behaviors and emotions, what you and your child do at home, in school, and around your neighborhood, the types of services your child receives, how your child feels about these services, and other information about your family. The results of the project will be used to help improve services for children, young adults, and their families.

Description of Participation

Participation in this evaluation is voluntary. You will be asked to participate in up to three interviews: an interview at intake, 6 months, and 12 months and/or at discharge if your child is enrolled in the program for less than 12 months. The interviews will take approximately 33 minutes. Data will be collected by (system of care name) personnel through a combination of interviews with you and use of some routinely collected information from your child’s records. You will be asked these questions as part of your child’s regular visit. There are no right or wrong answers to the questions. You may stop the interview at any time for any reason. You may also choose to skip any of the questions.

If your child is age 11 or older, or reaches age 11 at any time during the study, we will ask your child if we can interview him or her. At that time, we will ask for your permission to talk to your child. We will also describe the interview process to your child.

Risks

You may feel uncomfortable about answering some questions about you and your child’s experiences. You will be able to inform the interviewer if you are uncomfortable, and s/he will work with you in deciding if you want to continue with the interview or not.

Benefits

You will not get any direct benefit from being interviewed. However, the information you provide may help improve the services offered to children, youth, and their families.
Confidentiality

The information you share with us will only be used for the purposes of this study. We will keep you and your child’s information private to the extent permitted by law. Your child’s health care services or insurance coverage will not be affected by anything you say during the interview. We will record the interview to help us with our notes. The session recordings will be stored in a secure network folder and will be destroyed at the end of the project. The recording will be reviewed only by a few evaluation team members. Your name or your child’s name will not be used in any reports we write. This signed consent form and any forms and records from the study will be kept in a secure place that only project staff will be able to access.

Contact Information

If you have any questions about this project, you may call SAMHSA’s Project Officer for this evaluation, Dr. Kirstin Painter, at 240-276-1932.

If you have any questions about your rights and welfare as a research participant, you may contact [insert name of grantee IRB representative] at [insert contact phone of grantee IRB representative].

Voluntary Consent

*Rights Regarding Decision to Participate*: I understand that I will not be in trouble if I do not want to be in the evaluation, do not want my child to be involved, or if I decide to quit later. I do not have to answer questions that I do not want to answer. If I change my mind and quit, all of my answers to questions will be destroyed, if that is what I want. No one will say that I cannot be in other projects because I do not want to be in this project. No one can say that I cannot get services because I do not want to be in this project.

I have read this form or it has been read to me, and I understand what it says. My questions have been answered. A copy of this form will be given to me. By signing my name below, I freely agree to take part in this project.

**Caregiver/Guardian (Type or Print Full Name):** ______________________________

**Signature of Caregiver/Guardian:** ______________________________________

**Date:** ___/___/_____
CMHI SOC Evaluation: Child and Family Outcomes

Sample Parental Permission Form
Sample Parental Permission Form

Purpose

The Substance Abuse and Mental Health Services Administration (SAMHSA) in the United States Department of Health and Human Services is sponsoring an evaluation of children’s mental health services and systems of care. A system of care is a coordinated network of community-based services and supports that are organized to meet the challenges that children and youth with serious mental health needs and their families face. We are asking for your permission to have your child participate in an interview with a trained interviewer who will ask a set of questions about his/her involvement in (system of care name). The purpose of this interview is to find out the ways in which children and youth are involved in their system of care. In this research, we will ask you about your child’s behaviors and emotions, what he/she does at home, in school, and around your neighborhood, types of services your child receives, and how he/she feels about these services. The results of the study will be used to help improve services for children, young adults, and their families.

Description of Participation

Participation in this survey is voluntary and your child’s participation is completely his/her choice. Your child will be asked to participate in up to three interviews: an interview at intake, 6 months, and 12 months or at discharge if your child is enrolled in the program for less than 12 months. The interviews will take about 25 minutes. Data will be collected by (system of care name) staff through interviews with your child and use of some routinely collected information from your child’s records. Your child will be asked these questions during a regular visit, so additional visits will not be required. There are no right or wrong answers to the questions.

Risks

Your child may feel uncomfortable about answering some questions about his/her experiences. At any time, your child can stop, take a break, or skip any questions s/he does not want to answer.

Benefits

Your child will not get any direct benefit from being interviewed. However, the information your child provides may help improve the services offered to children, youth, and their families.

Confidentiality

The information your child shares with us will only be used for the purposes of this study. We will not share your child’s answers with you. We will keep your child’s information private to the extent permitted by law. If your child says anything about hurting themselves or others, we have to report it to the proper authorities.
Your child’s health care services or insurance coverage will not be affected by anything s/he says during the interview. We will record the interview to help us with our notes. The session recordings will be stored in a secure network folder and will be destroyed at the end of the project. The recording will be reviewed only by a few project staff. Your name or your child’s name will not be used in any reports we write. This signed consent form and any forms and records from the study will be kept in a secure place that only project staff will be able to access.

Contact Information

If you or your child have any questions about this project, you may call SAMHSA’s Project Officer for this study, Dr. Kirstin Painter, at 240-276-1932.

If you have any questions about your child’s rights and welfare as a research participant, you may contact [insert name of grantee IRB representative] at [insert contact phone of grantee IRB representative].

Parental Permission

I have read this form or it has been read to me. I understand what it says. My questions (if any) have been answered. A copy of this form will be given to me. By signing my name below, I give permission for my child to be in this study.

Parent Printed Name: ____________________________________________

Parent Signature: ______________________________________________

Name of Child Being Interviewed: _________________________________

Date: ___/___/_____
Appendix E

Child and Family Outcomes
Study Instrument Descriptions
Pediatric Symptom Checklist-17 Items (PSC-17)

Purpose

The PSC-17 is a psychosocial screen designed to improve the recognition and treatment of psychosocial problems in youth and young adults. The PSC-17 assesses psychiatric symptom severity (Gardner, Lucas, Kolko, & Campo, 2007), but it is not considered a diagnostic tool. Rather, the PSC-17 is used to alert individuals about possible behavioral issues that may benefit from further assessment.

Content and Measurement Quality

The PSC-17 contains 17 items and is a shorter version of the widely-used and well-validated 35-item version of PSC (Jellinek, et al., 1988). Test-retest reliability of the PSC-35 is high ($r = .84 \text{ - } .91$) as is its internal consistency ($\alpha= .91$) (Murphy & Jellinek, 1988; Murphy et al., 1996; Jellinek et al., 1988; Murphy, Reede, Jellinek, & Bishop, 1992). Studies indicate that the 17-item version yields scores that are generally congruent with the longer version (Blucker, et al., 2014; Stoppelbein, Greening, Moll, Jordan, & Suozzi, 2012). The PSC-17 demonstrated good construct validity, performing as well as other well-established instruments including the Child Behavior Checklist (Gardner et al., 2007). There are two parallel forms: one is completed by caregivers; the other is a youth and young adult self-report.

Scoring Instructions

The values for scoring the 17 responses are Never = 0 points, Sometimes = 1 point, and Often = 2 points. The total score is calculated by adding together the score for each of the 17 items. Items that are left blank or missing are scored as a 0 (zero). If four or more items are left blank, the questionnaire and the total score is considered invalid. A total score of 15 or more indicates a positive score (Gardner et al., 2007), which suggests the need for further evaluation.
Subscale scores for externalizing, internalizing, and attention problems can be calculated from specific items below:

**Externalizing Problems Subscale** (sum of items 4, 5, 8, 10, 12, 14, and 16)

- Refuses to share
- Does not understand other people’s feelings
- Fights with others
- Blames others for his or her troubles
- Does not listen to rules
- Teases others
- Takes things that do not belong to him or her

A score of 7 or higher on this subscale indicates a positive score for externalizing behavior.

**Internalizing Problems Subscale** (sum of items 2, 6, 9, 11, and 15)

- Feels sad, unhappy
- Feels hopeless
- Is down on him or herself
- Worries a lot
- Seems to be having less fun

A score of 5 or higher on this subscale indicates a positive score for internalizing behavior.

**Attention Problems Subscale** (sum of items 1, 3, 7, 13, and 17)

- Fidgety, unable to sit still
- Daydreams too much
- Has trouble concentrating
- Acts as if driven by a motor
- Distracted easily
A score of 7 or higher indicates a positive score for attention problems

**When to Administer and to Whom**

The PSC-17 is administered at baseline and at all follow-up data collection points. It is administered to caregivers of children and youth aged 5-21, to youth ages 11-17, and young adults ages 18-21. The instrument should be administered in an interview format.

**Time Required to Administer**

The PSC-17 takes approximately 5 minutes to administer.

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**Columbia Impairment Scale (CIS)**

**Purpose**

The CIS is designed to provide a global measure of psychosocial functioning among children in the areas of (a) interpersonal relations, (b) broad psychopathological domains, and (c) functioning in job, school, and community. In the national evaluation, the CIS will be used to assess functioning of children and youth between the ages of 5 and 21 years.

**Content and Measurement Quality**

The CIS contains 13 items and each item asks the caregiver to rate how much of a problem the child has in a variety of areas. Items are rated using a 4-point scale, ranging from *No problem* (0) to *Very big problem* (4). The items are answered based on the youth or young adult’s behavior in the past 6 months. There are two parallel forms: one is completed by caregivers; the other is a youth and young adult self-report.

The CIS has demonstrated good reliability and validity (Bird, Shaffer, Fisher, & Gould, 1993). The instrument is internally consistent (i.e., Cronbach’s alpha = .85 for parent version and .70
for the youth self-report version). The CIS is highly correlated with clinician ratings of psychosocial functioning. The CIS also discriminates between clinical and non-clinical samples.

**Scoring Instructions**

Each item is scored 0 to 4. To get a total score, add the scores for each of the 13 items. The total score should fall somewhere between 0 and 52. Scores can range from 0 to 52 with higher scores indicating more impairment. A score of 15 or higher is considered clinically impaired.

**Time Required to Administer**

The CIS takes approximately 5 minutes to administer.

**Special Considerations and Tasks**

Some items will not be applicable to all children, such as questions referring to schoolwork or interactions with siblings. In these situations, interviewers should indicate that these items were not applicable.

**Caregiver Strain Questionnaire (CGSQ) – 13 Items (CGSQ-13)**

**Purpose**

The CGSQ assesses the extent to which caregivers are affected by the special demands associated with caring for a child with emotional and behavioral problems. It is currently being used in several studies of children’s mental health services. The information collected through the CGSQ helps provide a picture of the issues caregivers face in taking care of a child with special challenges. A better understanding of these issues can lead to the inclusion or improvement of existing family support services. The CGSQ also provides a way to assess whether participating in system of care services reduces the strain caregivers and families may
experience (e.g., determining whether strain lessens over time as better services and supports are provided by the system of care).

**Content and Measurement Quality**

The CGSQ contains 13 items that assess strain experienced by caregivers in the last 6 months related to the care of a child with emotional and behavioral challenges. It comprises three related dimensions of caregiver strain. *Objective caregiver strain* refers to observable disruptions in family and community life and other difficult events (e.g., interruption of personal time, lost work time, financial strain). *Subjective internalized strain* captions negative “internalized” feelings such as worry, guilt, and fatigue. *Subjective externalized strain* assessed negative feelings that are outwardly directed such as anger, resentment, or embarrassment.

The CGSQ is a 5-point scale with response options ranging from *Not at all* (1) to *Very much* (5), indicating the degree to which that item was a problem in the last 6 months. Interviewers should note that the CGSQ is designed to assess the level of strain both on the family and on the individual caregiver through two different series of questions. The first series attempts to assess how life has been in the household for the past 6 months, and asks the caregiver to recall how things have been for *the family as a whole*. The second series of items asks the caregiver to specifically recall how *he or she* has personally felt during the past 6 months.

The CGSQ-17 is based on the original 21-item questionnaire. The CGSQ has demonstrated reliability and validity, with excellent internal consistency ($\alpha = 0.92$). It has also demonstrated convergent validity with other caregiver distress and family functioning instruments (Brannan, Heflinger, & Bickman, 1997). The CGSQ was shortened to 13 items for this evaluation by its developer (CGSQ-13; Brannan & Pullmann, 2015). The CGSQ-13 was developed using Rasch-based Item Response Theory, paired with traditional psychometric analyses. The CGSQ-13 demonstrated reliability and construct validity comparable to the original 21-item version.

**Scoring Instructions**

To calculate subscale scores, we recommend that no more than 15 percent of items are missing for a given subscale. The global scale score should not be calculated if one or more of the subscales is missing. Subscale scores for the CGSQ are calculated as follows:
Objective strain – mean of items 1-6 (do not score if more than one item missing)

Subjective externalized strain – mean of items 8, 9, and 13 (do not score if any item is missing)

Subjective internalized strain – mean of items 7, 10, 11, and 12 (do not score if any item is missing)

Global score – sum of the three subscale scores (do not score if any subscale is missing)

When to Administer and to Whom

The CGSQ is administered to caregivers (not staff-as-caregivers) in an interview format. It is administered at baseline and at all follow-up data collection points.

Time Required to Administer

The CGSQ takes approximately 5 minutes to administer.

Special Considerations and Tasks

No special preparation or information gathering is required before implementing this instrument.
References


