

## Evaluation Plan Overview

The focus of the evaluation is on documenting the process and measuring the effectiveness of the planning and implementation for expansion and sustainability. Strategies learned and utilized by staff and families, and the impact those strategies have on family and youth outcomes should be assessed. Demonstration of improved outcomes and program improvement should be another major focus of the evaluation. The evaluation should rely on systematic data collection at the individual child and family level, as well as at the organizational/community level.

The evaluation design should address **processes, structures, and outcomes**. It should evaluate the project at all three systems levels. The child and family outcomes can be measured using Community Child Health Team (CCHT) or Community Circle of Care (CCC) evaluation instruments (also see CCC data brief attached as a sample). Process measures and findings regarding strengths and barriers to project implementation will function as a **“formative evaluation”** defining outcomes for family, child, community/region, and state. (See following State Performance Measures care coordination, family support and infrastructure). Information based remedies or redirections can then be used to improve likelihood of strategy achievement. Finally, the evaluation should show improvement of the practices of inter- and intra-agency collaboration. Toward that end we will employ an analysis of the project structure and collaboration, with the Title V Index. Findings regarding achievement of intended outcomes measure project impact and will function as a **“summative evaluation.”** This information can be used to tailor arguments for future project spread and sustainability.

# Community Circle of Care Evaluation Instruments

(as selected for CAEH-CCHT project June 2011)

## *Caregiver Information Questionnaire (CIQ)*

- Collects information about the child and family including risk factors, family composition, physical custody of the child, and the child's mental and physical health service use
- Two versions; one for baseline interview and one for follow-up interviews

## *Caregiver Strain Questionnaire (CGSQ)*

- Assess difficulties, strains, and other negative effects related to caring for a child with emotional and behavioral problems
- Completed at baseline and follow-up

## *Child Behavior Checklist (CBCL)*

- Standardized measure of children's symptomatology
- Caregivers report their child's problems, disabilities, and strengths
- Two versions; one for children ages 1 ½-5 y and one for children ages 6-18 y
- Completed at baseline and follow-up

## *Cultural Competence and Service Provision (CCSP)*

- Assesses the importance of culture in the lives of the caregiver and their perspective on providers' consideration of family beliefs, traditions, and practices
- Only administered at follow-up

## *Family Life Questionnaire (FLQ)*

- Collects information about family communication, decision-making, and family support and bonding
- Assesses how these aspects may change as a result of SOC services
- Completed at baseline and follow-up

## *Youth Services for Families (YSS-F)*

- Measures perceptions of services across 5 domains: access, participation in treatment, cultural sensitivity, satisfaction, outcomes
- Only administered at follow-up

# Community Child Health Team Questionnaire- Intake

ID# \_\_\_\_\_

## Section I.

The first section of this survey includes general questions about you and your family. We are collecting this information so that we can learn about the families served through this program. All of your answers will remain confidential and you may skip any questions you prefer not to answer.

**1. What is your relationship to the child or youth receiving services?**

- Biological parent
- Adoptive parent or Step-parent
- Foster parent
- Sibling
- Aunt or Uncle
- Grandparent
- Cousin
- Other (please specify): \_\_\_\_\_

**2. Which group best describes you? (Select all that apply)**

- American Indian or Alaska Native
- Asian
- Black or African American
- Central American
- Cuban
- Native Hawaiian or Other Pacific Islander
- Puerto Rican
- South American
- White
- Other (please specify): \_\_\_\_\_

**3. What language or languages do you and your child speak?**

- English
- Spanish
- Other (please specify): \_\_\_\_\_

**4. What is the highest level of education you have completed?**

- Some high school
- High school diploma or GED
- Associate degree
- Some college, no degree
- Bachelor's degree
- Master's degree
- Professional school degree
- Doctoral degree

**5. What is your annual household income?**

- Less than \$15,000
- \$15,000-\$29,999
- \$30,000-\$44,999
- \$45,000-\$59,999
- \$60,000-\$74,999
- \$75,000 and over

**6. At any time in the past 6 months did you have a paid job, including self-employment?**

- Yes
- No (SKIP TO QUESTION #10)

**7. Out of the past six months, how many months did you work?**

\_\_\_\_\_

**8. In an average week, how many hours did you work?**

\_\_\_\_\_

**9. How many days did you miss work, if any, due to your child's emotional or behavioral problems?**

\_\_\_\_\_ (SKIP TO PAGE 2)

**10. Do you think you would have a paid job if your child did not have problems?**

- Yes
- No

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## Community Child Health Team Questionnaire

### Section II.

This section includes questions about you and your family and how having a child with behavioral and/or emotional problems may determine how your family spends time together. You may skip any question that is not applicable to your family or that you prefer not to answer.

	Never	Sometimes	About half the time	Most of the time	Always
11. How often do you have time to spend with your family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. How often do you have time to spend alone or with friends?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. How often do you have money to pay for basic needs, like housing, food, or clothing?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. How often do you have money to pay for special things like toys, entertainment, or vacations?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Please think back over the past 6 months and try to remember how things have been for your family. How much of a problem, if any, were the following?</i>					
	Not at all	A little	Somewhat	Quite a bit	Very much
15. Interruption of personal time resulting from your child's emotional or behavioral problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Your missing work or neglecting other duties because of your child's emotional or behavioral problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Disruption of family routines due to your child's emotional or behavioral problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Any family member having to do without things because of your child's emotional or behavioral problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Any family member suffering negative mental or physical health effects as a result of your child's emotional or behavioral problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Your child getting into trouble with the neighbors, the school, the community, or law enforcement?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Financial strain for your family due to your child's emotional or behavioral problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Less attention paid to other family members because of your child's emotional or behavioral problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Disruption or upset of relationships within the family due to your child's emotional or behavioral problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Disruption of your family's social activities resulting from your child's emotional or behavioral problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
GO TO NEXT PAGE					

*In the past 6 months, how much of a problem, if any, were the following?*

	Not at all	A little	Somewhat	Quite a bit	Very much
25. How isolated did you feel as a result of your child's emotional or behavioral problem?	<input type="radio"/>				
26. How sad or unhappy did you feel about your child's emotional or behavioral problem?	<input type="radio"/>				
27. How embarrassed did you feel about your child's emotional or behavioral problem?	<input type="radio"/>				
28. How well did you relate to your child?	<input type="radio"/>				
29. How angry did you feel toward your child?	<input type="radio"/>				
30. How worried did you feel about your child's future?	<input type="radio"/>				
31. How worried did you feel about your family's future?	<input type="radio"/>				
32. How guilty did you feel about your child's emotional or behavioral problem?	<input type="radio"/>				
33. How resentful did you feel toward your child?	<input type="radio"/>				
34. How tired or strained did you feel as a result of your child's emotional or behavioral problem?	<input type="radio"/>				
35. In general, how much of a toll has your child's emotional or behavioral problem taken on your family?	<input type="radio"/>				

*The following statements describe things that some families do together and how some families interact. For each statement, please select the response that best fits your family.*

	Never	Not very often	Sometimes	Most of the time	Always
36. Our family talks about fun things and things that make us laugh.	<input type="radio"/>				
37. Our family members agree about things such as what to watch on TV or what to eat for dinner.	<input type="radio"/>				
38. Our family spends time together as a family.	<input type="radio"/>				
39. Our family talks about our problems and troubles.	<input type="radio"/>				
40. Our family members rely on each other when problems arise.	<input type="radio"/>				
41. Our family does things together outside of our home.	<input type="radio"/>				
42. Our family talks about things that make us angry without fighting.	<input type="radio"/>				
43. Family members can solve problems our child has when they happen.	<input type="radio"/>				
44. Our family deals with crises or major problems without fighting.	<input type="radio"/>				
45. Our child talks with members of our family about things that make him/her happy, sad, or upset.	<input type="radio"/>				

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**46. Have any of your child's doctors or health care providers talked with you about having your child eventually see doctors or health care providers who see adults?**

Yes (SKIP TO QUESTION #48)

No

**47. Would a discussion about doctors who treat adults have been helpful to you?**

Yes

No

**48. Have your child's doctors or health care providers talked with you or your child about his or her health care needs as he or she becomes an adult?**

Yes (SKIP TO QUESTION #50)

No

**49. Would a discussion about your child's health care needs as an adult have been helpful?**

Yes

No

**50. Has anyone discussed with you how to obtain or keep some type of health insurance coverage as your child becomes an adult?**

Yes (SKIP TO QUESTION #52)

No

**51. Would a discussion about health insurance have been helpful to you?**

Yes

No

**52. How often do your child's doctors or health care providers encourage him or her to take responsibility of his or her health care needs such as taking medications, understanding his or her diagnosis, or following medical advice?**

Never

Rarely

Sometimes

Often

All of the time

END OF SURVEY

# Community Child Health Team Questionnaire- Follow-up

ID# \_\_\_\_\_

## Section I.

The first section of this survey includes general questions about you and your family. We are collecting this information so that we can learn about the families served through this program. All of your answers will remain confidential and you may skip any questions you prefer not to answer.

**1. What is your relationship to the child or youth receiving services?**

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- Grandparent
- Cousin
- Other (please specify): \_\_\_\_\_

**2. Which group best describes you? (Select all that apply)**

- American Indian or Alaska Native
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- Central American
- Cuban
- Native Hawaiian or Other Pacific Islander
- Puerto Rican
- South American
- White
- Other (please specify): \_\_\_\_\_

**3. What language or languages do you and your child speak?**

- English
- Spanish
- Other (please specify): \_\_\_\_\_

**4. What is the highest level of education you have completed?**

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**5. What is your annual household income?**

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- \$15,000-\$29,999
- \$30,000-\$44,999
- \$45,000-\$59,999
- \$60,000-\$74,999
- \$75,000 and over

**6. At any time in the past 6 months did you have a paid job, including self-employment?**

- Yes
- No (SKIP TO QUESTION #10)

**7. Out of the past six months, how many months did you work?**

\_\_\_\_\_

**8. In an average week, how many hours did you work?**

\_\_\_\_\_

**9. How many days did you miss work, if any, due to your child's emotional or behavioral problems?**

\_\_\_\_\_ (SKIP TO PAGE 2)

**10. Do you think you would have a paid job if your child did not have problems?**

- Yes
- No

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## Community Child Health Team Questionnaire

### Section II.

This section includes questions about you and your family and how having a child with behavioral and/or emotional problems may determine how your family spends time together. You may skip any question that is not applicable to your family or that you prefer not to answer.

	Never	Sometimes	About half the time	Most of the time	Always
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20. Your child getting into trouble with the neighbors, the school, the community, or law enforcement?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Financial strain for your family due to your child's emotional or behavioral problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Less attention paid to other family members because of your child's emotional or behavioral problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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GO TO NEXT PAGE					

*In the past 6 months, how much of a problem, if any, were the following?*

	Not at all	A little	Somewhat	Quite a bit	Very much
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27. How embarrassed did you feel about your child's emotional or behavioral problem?	<input type="radio"/>				
28. How well did you relate to your child?	<input type="radio"/>				
29. How angry did you feel toward your child?	<input type="radio"/>				
30. How worried did you feel about your child's future?	<input type="radio"/>				
31. How worried did you feel about your family's future?	<input type="radio"/>				
32. How guilty did you feel about your child's emotional or behavioral problem?	<input type="radio"/>				
33. How resentful did you feel toward your child?	<input type="radio"/>				
34. How tired or strained did you feel as a result of your child's emotional or behavioral problem?	<input type="radio"/>				
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*The following statements describe things that some families do together and how some families interact. For each statement, please select the response that best fits your family.*

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38. Our family spends time together as a family.	<input type="radio"/>				
39. Our family talks about our problems and troubles.	<input type="radio"/>				
40. Our family members rely on each other when problems arise.	<input type="radio"/>				
41. Our family does things together outside of our home.	<input type="radio"/>				
42. Our family talks about things that make us angry without fighting.	<input type="radio"/>				
43. Family members can solve problems our child has when they happen.	<input type="radio"/>				
44. Our family deals with crises or major problems without fighting.	<input type="radio"/>				
45. Our child talks with members of our family about things that make him/her happy, sad, or upset.	<input type="radio"/>				

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## Community Child Health Team Questionnaire

### Section III.

The following questions ask about the services you have received from this and other programs. Please think back to the services you received before coming to the clinic and rate the following statements based on your experience before and after receiving services through this program.

	BEFORE receiving services					AFTER receiving services				
	Very bad	Bad	OK	Good	Very good	Very bad	Bad	OK	Good	Very good
46. Your ability to get help in a crisis.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
47. Your home situation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
48. Your relationship with your child's school.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
49. Your level of stress.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
50. Your ability to get needed services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
51. Having someone to talk to.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
52. Feeling and/or being supported.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
53. Your family's mental health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
54. Family members have time to themselves.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How would you rate the following both before and after receiving services through this program?

	BEFORE receiving services					AFTER receiving services				
	Very bad	Bad	OK	Good	Very good	Very bad	Bad	OK	Good	Very good
55. Your child's school situation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
56. Your child's relationship with his or her family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
57. Your child's ability to get help and services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
58. Your child's behavior.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
59. Your child's happiness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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**60. Overall, how helpful has this program been to you and your family?**

- Not at all
- A little
- Somewhat
- Helpful
- Very helpful

**61. What has been the most helpful about your family's involvement with this program?**

*As a result of the services my family has received:*

	Strongly disagree	Disagree	Undecided	Agree	Strongly agree
<b>62. My child is better at handling daily life.</b>	<input type="radio"/>				
<b>63. My child gets along better with family members.</b>	<input type="radio"/>				
<b>64. My child gets along better with friends and other people.</b>	<input type="radio"/>				
<b>65. My child is doing better at school and/or work.</b>	<input type="radio"/>				
<b>66. My child is better able to cope when things go wrong.</b>	<input type="radio"/>				
<b>67. I am satisfied with our family life right now.</b>	<input type="radio"/>				

**68. What part of the team was most important to you and your family receiving services?**

**69. How has the Family Navigator in particular been helpful to your family?**

**70. Have any of your child's doctors or health care providers talked with you about having your child eventually see doctors or health care providers who see adults?**

- Yes (SKIP TO QUESTION #72)
- No

**71. Would a discussion about doctors who treat adults have been helpful to you?**

- Yes
- No

**72. Have your child's doctors or health care providers talked with you or your child about his or her health care needs as he or she becomes an adult?**

- Yes (SKIP TO QUESTION #74)
- No

**73. Would a discussion about your child's health care needs as an adult have been helpful?**

- Yes
- No

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**74. Has anyone discussed with you how to obtain or keep some type of health insurance coverage as your child becomes an adult?**

Yes (SKIP TO QUESTION #76)

No

**75. Would a discussion about health insurance have been helpful to you?**

Yes

No

**76. How often do your child's doctors or health care providers encourage him or her to take responsibility of his or her health care needs such as taking medications, understanding his or her diagnosis, or following medical advice?**

Never

Rarely

Sometimes

Often

All of the time

#### **Section IV.**

*This last section includes questions about your satisfaction with the services you have received over the past 6 months.*

	Strongly disagree	Disagree	Undecided	Agree	Strongly agree
<b>77. The services my child and family received were right for us.</b>	<input type="radio"/>				
<b>78. I helped choose my child's services and treatment goals.</b>	<input type="radio"/>				
<b>79. I felt my child had someone to talk to when he or she was troubled.</b>	<input type="radio"/>				
<b>80. My family got as much help as we needed for my child.</b>	<input type="radio"/>				
<b>81. Overall, I am satisfied with the services my family has received.</b>	<input type="radio"/>				
<b>82. Staff treated me with respect.</b>	<input type="radio"/>				
<b>83. Our provider understood the beliefs that our family may have about mental health.</b>	<input type="radio"/>				
<b>84. Our provider respected my family's religious or spiritual beliefs.</b>	<input type="radio"/>				
<b>85. If services we needed or wanted were not being provided, our provider told us how we could get those services.</b>	<input type="radio"/>				

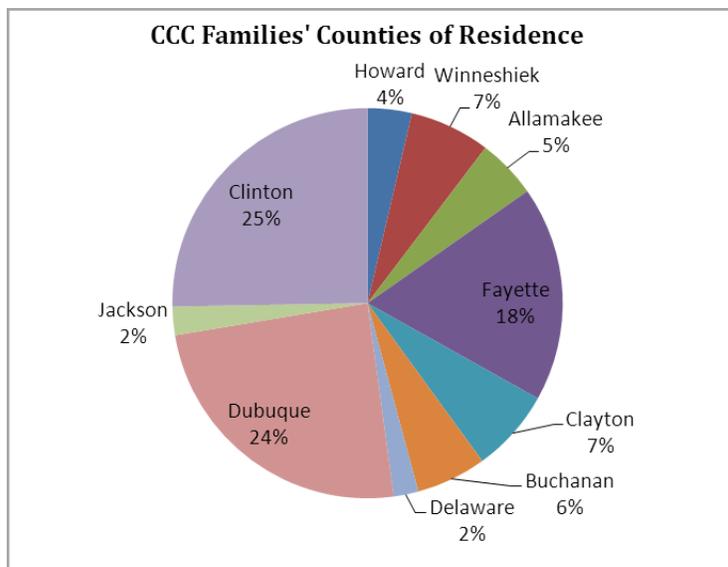
END OF SURVEY

# Community Circle of Care

The Community Circle of Care (CCC) is a regional Systems of Care (SOC) site comprised of a coordinated network of community-based services and supports that is organized to meet the challenges of children and youth with serious mental health needs and their families. Merging medical model principles with social supports, CCC services are family-driven and youth-guided, community-based, and culturally competent. Community Circle of Care is a collaboration among the Iowa Department of Human Services, the University of Iowa Child Health Specialty Clinics, and the University of Iowa Center for Disabilities and Development.

## Demographics

- ❖ Between August, 2008 and December, 2011 930 children and youth were enrolled in Community Circle of Care; 66% were boys and 34% were girls.
- ❖ 95% of CCC children were White, 7% were Black or African American, and 3% were Mexican American, South American, or Central American.
- ❖ The Community Circle of Care service area includes ten counties in northeast Iowa. Nearly 50% of CCC families came from either Dubuque or Clinton County.
- ❖ At intake, 35% of CCC families were below the poverty level and 24% were at or near poverty.



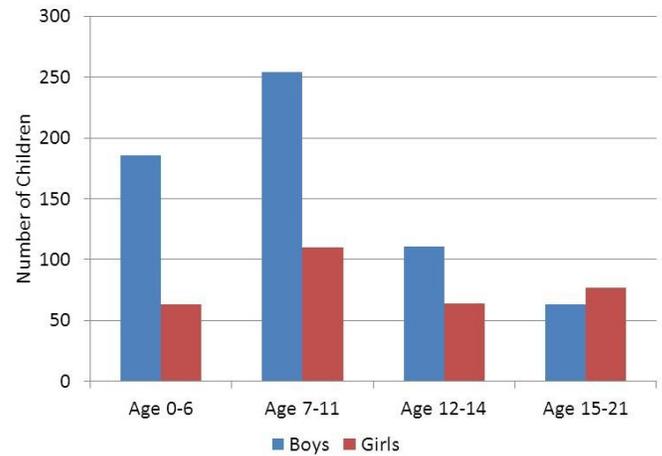
## Referral, Diagnosis, & Family History

- ❖ Over 65% of families were referred to CCC by schools, mental health agencies, or physical health providers.
- ❖ Among the most common reasons for referral were hyperactive and attention-related problems.
- ❖ Over 75% of CCC children and youth received a primary diagnosis of an attention or conduct-related disorder.
- ❖ Over 60% of CCC youth had more than one diagnosis; 16% received three diagnoses.
- ❖ 58% of CCC youth have lived with someone who was depressed and 32% have lived with someone with a mental illness other than depression.
- ❖ 31% of CCC youth have lived with someone who had a substance abuse problem and 27% have witnessed domestic violence.

## Improvement at School

- ❖ Among children and youth receiving services for at least 12 months, 46% showed improvement in school attendance.
- ❖ 40% of youth showed improvement in school performance.
- ❖ After receiving services for at least 6 months, more caregivers responded positively about their child's school functioning and their ability to complete school-related tasks.
- ❖ Fewer caregivers reported missing days from work due to their child's behavioral or emotional problems.

**Age of CCC Children & Youth at Intake**



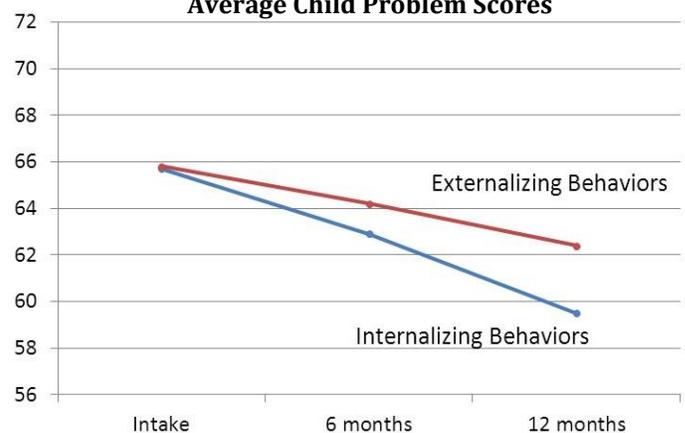
**Primary Diagnosis of Children Served by CCC**

Attention-Deficit and Disruptive Behavior Disorders <i>(Includes ADHD, Conduct Disorder, Oppositional Defiant Disorder, and Disruptive Behavior Disorder)</i>	77%
Depressive Disorders	8%
Anxiety Disorders	6%
Pervasive Developmental Disorders	5%
Adjustment Disorders	6%
Other <i>(Includes Reactive Attachment Disorder, Learning Disorders, and Regulatory Disorder)</i>	4%

## Improvement in Behavior Problems

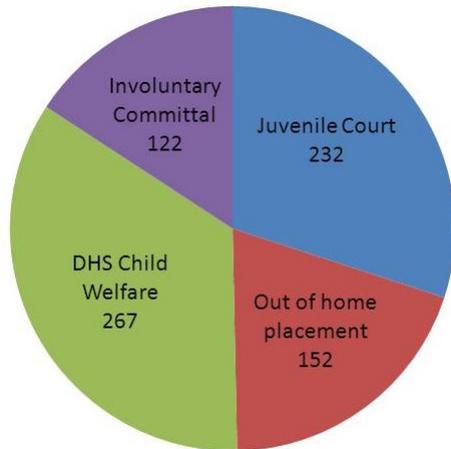
Many children and youth come to CCC with two types of behavior problems: externalizing behaviors such as aggression and rule-breaking, and internalizing behaviors such as anxiety and depression. Among CCC youth receiving services for at least one year, there was a decrease in both types of behavior problems.

**Average Child Problem Scores**



## Reduction in Out-of-Home Placements

A comprehensive chart review of 1354 CCC children and youth found that in the absence of CCC services, 773 youth (57%) would have received more costly and restrictive services such as out-of-home placement and involuntary committal.



### Maya\* - 15 years old

- Diagnosed with ADHD, ODD, and Conduct Disorder along with primary support and social environmental problems.
- Received a comprehensive health exam, psychiatric diagnostic interview, individual psychotherapy, and medication management.
- Maya also received 12 hours of in-home skill-building and counseling services and stayed one night in an emergency shelter.
- Without CCC services, Maya was at risk of residential placement. Average stay 90 days.

Potential Residential Treatment Costs = \$9,900

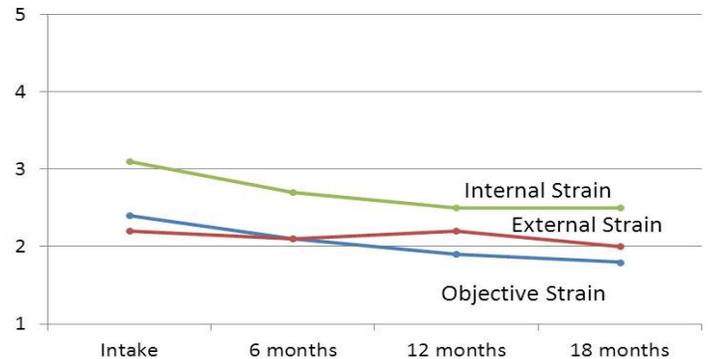
Actual CHSC/CCC Costs = \$3,230

Potential Costs Savings = \$6,670

## Improvement in Caregiver Strain

Caregivers of children with emotional or behavioral problems often experience higher levels of stress and strain including disruptions in family life, feelings of anger, and guilt. Among caregivers receiving services for 18 months or more, there was a reduction in all three types of strain.

Average Caregiver Strain Scores



### Brian\* - 11 years old

- Diagnosed with ADHD, ODD, and Epilepsy along with pervasive developmental disabilities, safety concerns, and educational problems.
- Received a comprehensive health exam, psychiatric diagnostic interview, medication management services, care coordination, and participated in family team meetings.
- Brian also received CCC funds to attend a respite home two weekends a month for 6 months.
- Without CCC services, Brian was at risk of being placed in a PMIC facility. Average stay 259 days.

Potential Hospital Costs = 45,854

Actual CHSC/CCC Costs = \$6,640

Potential Costs Savings = \$38,944

## CCC Youth Stories

### Caroline\*

Hi, my name is Caroline and I am 18 years old. Growing up was difficult and when I was younger, the word “no” was a constant trigger. I would have horrible fits and was first hospitalized for my mental health when I was 8 years old. In school I was made fun of and I had a hard time socializing. It was hard to make friends because I was constantly moving to different out-of-home placements.

At the age of 16, I was told that no program in the state of Iowa would accept me, so I was placed out-of-state and spent a year in a treatment facility in Missouri. When I was 17, I graduated from that program and was sent back to Iowa to yet another treatment facility. Finally, the day before by 18th birthday, I was released to live on my own in my home community.

With lots of services and supports, I have been living on my own for almost a year. I now have my own apartment and I love it! I have some help with cleaning, money management, and medication and I see a counselor and psychiatrist. Staff from Community Circle of Care continue to help me and my family meet other youth and families who have kids with mental health challenges. I am finding out that there are lots of other youth out there like me. I now have a lot of friends and I am a bit of a social butterfly. If I were given the opportunity to talk directly to individuals who can help kids stay in their community, I would say, “look what I have been through!” It is important to help kids stay near their families. Now that I can live in the community, I finally feel like I can be myself.

\* All names have been changed.

### Henry\*

Hello, my name is Henry and I am from Northeast Iowa. I was about 7 years old when I first got involved in the mental health system. At that time I was hospitalized for one week. Over the next few years I had over 16 placements throughout the state of Iowa and over nine different diagnoses were added to my chart.

In 2008, my family was told that no program in Iowa would accept me, so I was placed in Utah for about 10 months. Shortly after I returned to Iowa to live with my family we moved. This was an opportunity for me to start over. No one knew me, so it was a fresh start for me, especially at school. I was able to make friends and was surrounded by adults who gave me a chance.

I still see a psychiatrist who manages my medication and I have been able to stay in my community since June, 2009. In May, 2012 I graduated from high school and I am starting Community College in the fall where I plan to major in renewable energy technology. Life is pretty good and I now know people believe in me.

If I were given the opportunity to talk directly to individuals who can help kids stay in their community, I would say please help youth stay close to home. The farther you are away, the harder it is for your family to visit, which can make you more depressed. You feel detached and it makes treatment even harder.

If I were given the opportunity to talk directly to youth who are placed out-of-state, I would say keep moving on. You will get better. Don't worry about the time it takes, people believe in you.

# Process Measurement Tool (page 1 of 2)

## Care Coordination (used for State Performance Measure #2)

0	1	2	3	4	5	Element
						1. Comprehensive orientation and training for all care coordinators (e.g. CHSC values, confidentiality, cultural competence, family-directed, health literacy, EPIC, tracking log, roles by professional classification, motivational interviewing, etc.)
						2. Families know they are receiving care coordination, the name of the care coordinator(s), and how to access him/her and a backup.
						3. Families provide qualitative and quantitative feedback regarding their experiences with care coordination.
						4. Families determine the level/type of care coordination support they desire.
						5. Care coordinators provide all resources to match health literacy level of CYSHCN/family.
						6. Care coordination process assesses CYSHCN/family strengths, needs and monitors ongoing progress.
						7. Care coordinators connect families to comprehensive resources to match their current and emerging needs.
						8. Care coordinator(s) assist CYSHCN/family in developing self-advocacy skills.
						9. Emergency plans are in place for children, youth, and families served (as needed).
						10. Transition planning for CYSHCN begins on or before 14 years of age.
						11. Reimbursement mechanisms for care coordination are in place.

0 = Process is not defined or status is unknown

1 = There is an informal understanding about the process by some of the people who do the work. There is not a widely recognized or formal written description of the process.

2 = Process is documented. Process description includes all required participants (including families where appropriate). All understand the process.

3 = The process is well-defined and enacted readily. Quality measures are identified to monitor outcomes of the process and may be used by few/some.

4 = Ongoing measures of the process are monitored routinely by key stakeholders and used to improve the process. Documentation is revised and the process is improved.

5 = Process outcomes are predictable. Processes are fully embedded in operational systems. The process consistently meets the needs and expectations of all families and/or providers.

Total the numbers in the boxes (possible 0-55 score) \_\_\_\_\_

**Process Measurement Tool (page 2 of 2)**  
**Family Support (used for State Performance Measure #2)**

0	1	2	3	4	5	Element
						1. Family members are employed as paid staff or consultants to CHSC.****
						2. CHSC Parent Consultants participate on external advisory committees or task forces and are offered training, mentoring and reimbursement for their participation on that task force or advisory group.
						3. CHSC Parent Consultants receive competency-based training and ongoing mentoring for their roles within CHSC.
						4. There is a mechanism for ongoing communication among the parent consultant network and opportunities for parent consultants to share knowledge from their participation in advisory committees or task forces with other CHSC staff.
						5. Financial support (e.g., travel, stipends) is offered for non-CHSC staff parent participation in CHSC-sponsored activities that require family input above and beyond that offered by CHSC parent consultants.
						6. CHSC Parent consultants and other family members participate in the planning, implementation and evaluation of Title V MCH activities.
						7. Parent consultants and other family members work with their professional partners to provide training (pre-service, in-service and professional development) to MCH/CYSHCN staff and providers.
						8. Family members of diverse cultures are involved in delivering CHSC programs and services.
						9. Impact data is collected for family support activities.

0 = Process is not defined or status is unknown

1 = There is an informal understanding about the process by some of the people who do the work. No widely recognized or formal written description of the process.

2 = Process is documented. Process description includes all required participants (including families where appropriate). The process is understood by all.

3 = The process is well-defined, and enacted reliably. Quality measures are identified to monitor outcomes of the process and may be in use by few/some.

4 = Ongoing measures of the process are monitored routinely by key stakeholders and used to improve the process. Documentation is revised as the process is improved.

5 = Process outcomes are predictable. Processes are fully embedded in operational systems. The process consistently meets the needs and expectations of all families and/or providers.

Total the numbers in the boxes (possible 0- 45 score) \_\_\_\_\_

# Structure (System/Infrastructure) Measurement Tool

By use of Title V/CYSHCN Program: Index (2-page tool)

	<b>Preparation</b>	<b>Preliminary action steps</b>	<b>Implementation</b>	<b>Mastery</b>	<b>Sustainability</b>
<b>Score</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
1) Strategic Leadership					
2) Partnerships across public and private sectors					
3) Quality Improvement					
4) Use of available resources					
5) Coordination of service delivery					
6) Data infrastructure					

**(See attachment for scoring interpretation)**

**Total the number the boxes (possible 0-30)**

**TOTAL SCORE:** \_\_\_\_\_

## TITLE V Index

Preparation	Preliminary action steps	Implementation	Mastery	Sustainability
<p><b>1. Strategic leadership</b> A strategic plan for the Title V program has been established.</p>	The strategic plan has been shared and communicated across the Title V program.	The will and trust for realizing the strategic plan has been established within the Title V program and key stakeholders and partners.	The strategic plan is embedded within the Title V program. A number of goals associated with the strategic plan have been achieved and long term plans for sustaining these achievements are being developed.	Goals associated with the strategic plan are met consistently. Lessons learned are shared and acted on across the Title V program in an environment of mutual trust. Plans for the long term sustainability of the goals are being executed.
<p><b>2. Partnerships across public and private sectors:</b> The Title V program strategic plan includes areas that are specific to partnerships across public and private sectors/constituency.</p>	Key public and private sector constituencies have been identified and initial relationships have been established.	A number of programs have begun to partner effectively with key public and private sector constituencies.	A number of targets in the Title V strategic plan have been met in partnership with key public and private sector constituencies.	Partnerships with key public and private sector constituencies have been sustained and have led to the realization of relevant targets in the Title V program strategic plan.
<p><b>3. Quality Improvement:</b> The Title V program strategic plan includes areas that are specific to quality improvement.</p>	The quality improvement strategic plan has been shared and communicated across key stakeholders and partners	A number of quality improvement projects, in partnership with key stakeholders, partners and families are underway.	A number of quality improvement projects, in partnership with key stakeholders, partners and families have achieved positive results.	Quality improvement is embedded in all programs and process. Sustained results have been achieved. Lessons learned are consistently shared across key stakeholders, partners and families.
<p><b>4. Use of available resources:</b> The Title V program understands the need to maximize the use of available resources.</p>	The Title V program is cognizant of available resources, including financial, personnel skill sets and knowledge systems.	Are actively engaged in maximizing productivity in some system of care areas by directly or indirectly influencing available resources.	Has achieved some success in achieving targets by directly or indirectly influencing available resources effectively.	Available resources are consistently levered so as to maximize the likelihood that the targets associated with the overall strategic plan are achieved.
<p><b>5. Coordination of service delivery:</b> The Title V program strategic plan includes areas that are specific to service coordination.</p>	Have identified where there are gaps in the provision and coordination of services.	Plans are in place to reduce gaps in the provision and coordination of services.	Some success has been achieved in reducing gaps in the provision and coordination of services.	Rapid improvements in service and coordination are consistently realized in partnership with key stakeholders and families to remove these.
<p><b>6. Data Infrastructure:</b> The Title V program strategic plan includes areas that are specific to data infrastructure.</p>	The need to establish effective data systems has been communicated across key stakeholders and partners.	A number of data systems have been established.	A number of data systems exist and are routinely used to share system of care performance information across key partners and stakeholders.	Information of the whole system of care is shared routinely across key partners and stakeholders in a manner that informs the knowledge and actions required to meet the targets of the overall strategic plan of the Title V program.

*This Index was developed by NICHQ as part of the Learning Collaborative “Improving the System of Care for Children and Youth with Special Healthcare Needs”*