

CAPES Research Project Study Protocol #2

Title: Differences in Key Performance Indicators (KPIs) after Enrollment and Six Months of Participation in the Child and Adolescent Program Enrichment Services (CAPES) Program.

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1. Objective

The purpose of this study is to determine the effects of enrollment and six months of participation in the CAPES program on metrics related to symptomology, care indicators, utilization metrics and service utilization.

CAPES is committed to gathering information regarding the effectiveness of collaborative care model. Outcome data is critical in order to justify expansion of a collaborative care service delivery model.

2. Specific Aims

Aim 1: To determine differences in the measurement of the following domains after enrollment and participation in the CAPES program.

- 1: Reason for Referral to CAPES
- 2: Diagnosis
- 3: Age
- 4: Grade
- 5: School Placement (Public/Private)
- 6: Special Services Received at School
- 7: Hospitalizations
- 8: Residential Placement
- 9: Number of Current Health Care Providers
- 10: Number of Current Health Care Visits and Cost/Co-Pay per month
- 11: Number of Current Medications per month
- 12: Cost of Current Medications per month
- 13: Child Behavior Check List (CBCL)
- 14: Parent Stress Index (PSI)
- 15: Strengths and Difficulties Questionnaire (SDQ)
- 16: Children Depression Inventory (CDI) - Parent
- 17: Multidimensional Anxiety Scale for Children (MASC) - Parent
- 18: Kidscreen
- 19: CAPES Services Matched to Special Services

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3. Background

It is estimated that 10% to 20% of youths (approximately 15 million children in the United States) meet the diagnostic criteria for a mental health disorder, and many more are at risk for escalating problems with long-term individual, family, community, and societal implications.

Mental health problems in children and adolescents have created a “health crisis” in this country. (Satcher, 2000) These problems affect a growing number of youths, they impact these children and their families in all spheres of their lives, and the consequences are costly and often tragic.

When health care providers are unable due to the service delivery model to address the problems presented as interrelated, and as existing within a larger system the overall care of the child or adolescent is diminished. This diminished care leads to significant delays in resolution of the presenting problems and in less than optimum outcomes for all involved.

The typical trajectory for this journey in search of assistance from the health care providers is that a parent or provider would identify a problem and seek assistance. Families typically travel this path alone moving with best intentions from on specialist to the next in search of resolution. This lack of collaboration on the part of the variety of specialists is not due to a lack of desire or need on the part of the health care providers. This lack of collaboration is due to the fact that a system for interaction and collaboration between providers does not exist in our health care model.

Children and adolescents with moderate to severe problems in two or more areas pose significant problems to the Care Providers. These problems are exacerbated by a service delivery design which does not encourage or establish a format for consultation and collaboration between providers.

The Guide to Building Collaborative Mental Health Care Partnerships in Pediatric Primary Care states; “Given that children and adolescents with chronic mental illnesses are more prevalent than those with leukemia, diabetes and AIDS combined, the importance of integrated health care is critical. Part of the solution lies in the collaborative mental health partnerships whereby coordinated communication between all health care providers to coordinate systems of care for the child/adolescent and family is essential”.

The CAPES program provides a dynamic approach designed to establish an arena in which innovative consultation and collaboration is facilitated to provide recommendations for children and adolescents. The CAPES panel of experts provides the parents an opportunity to present the history, current status and issues affecting their child/adolescent as well as their desired resolution. CAPES then coordinates the dynamic perspective of multiple service providers from

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different professional areas of expertise while consistently maximizing communication between providers, school personnel and families, with the goal of changing the trajectory of care for children and adolescents. CAPES has been designed as a new approach to providing care to these children and adolescents, and the effectiveness of this approach will be explored through analysis of pre-test and post-test scores on the Child Behavior Checklist.

In a preliminary study (Protocol CAPES 1-2014) it was found that, specific to the CBCL that there were significant differences in five of six areas measured within the instrument.

1. There was a significant effect for Affective, $t(18) = 3.8$, $p = .001$, with the post-affective score being lower than the pre-affective score.
2. There was not a significant effect for Somatic, $t(9) = 1.94$, $p = .088$. However, the post-somatic score was lower than the pre-somatic score.
3. There was a significant effect for Anxiety, $t(18) = 3.02$, $p = .007$, with the post-anxiety score being lower than the pre-anxiety score.
4. There was a significant effect for ADHD, $t(16) = 5.14$, $p < .001$, with the post-ADHS score being lower than the pre-ADHD score.
5. There was a significant effect for Oppositional Defiant, $t(23) = 5.74$, $p < .001$, with the post-oppositional defiant score being lower than the pre-oppositional defiant score.
6. There was a significant effect for Conduct, $t(18) = 4.01$, $p < .001$, with the post-conduct score being lower than the pre-conduct score.

With these positive results, it is desired to examine the effects that these positive results have on other measurement instruments and utilization metrics.

Study Team Expertise

The CAPES team consists of the following members: Pediatrician, Child Psychiatrist, Psychologist, Family Therapist, Speech-Language Therapist, Occupational Therapist, Educational Expert, Statistician, Parents, and CAPES team administrator. The PI and Co-PIs have experience conducting research and will uphold all rules and regulations which are in place to protect human subjects.

4. Methodology

a. Inclusion/Exclusion Criteria

I. Parents (age 18 and over) of children and adolescents with moderate to severe

Problems in two or more areas.

a. Recruitment Plan and Study Design

i. Number of Subjects

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- n = 60
- ii. Method of Contact
 - Parents (age 18 and over) will complete forms identical to the forms completed as part of the CAPES intake during the six month follow-up session.
- iii. Method of Consent
 - Inform Consent is being completed
- iv. Method of Interaction/Procedure/Intervention
 - The members of the CAPES panel of experts review all information provided by the intake forms prior to the scheduled meeting with the family.
 - The entire CAPES team of experts meet with parents. Additionally individuals who are involved with the child/adolescent are invited to attend the meeting if the parents request their attendance. The CAPES team listens to the family explain the history the current status, issues affecting the child/adolescent.
 - Within two weeks of the initial CAPES meeting two or more members of the CAPES team meet with the parents and share written care recommendations which the team has developed following the initial meeting.

II. Compensation

There will be no compensation for the participants in this study.

b. *Data Retention and/or Data Destruction Plan*

- i. How long will you keep subject data?
The data will be destroyed one year after successful completion of study.
- ii. If you plan to destroy the data, how will you destroy it?
Any paper records used in the research will be shredded, physical media will be erased and physically destroyed, and electronic media will be scrubbed after the files are deleted.

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Researchers may retain de-identified data for future analysis in the context of the project the data were collected for. Data are considered to be completely de-identified when all links between individual identity and the data are destroyed. Research data are not considered de-identified simply because names have been removed if they still contain information that might identify the participants such as date of birth, address, etc.

Data collected only after an IRB approval has been granted. Data will be collected only for the following areas:

- 1: Reason for Referral to CAPES
- 2: Diagnosis
- 3: Age
- 4: Grade
- 5: School Placement (Public/Private)
- 6: Special Services Received at School
- 7: Hospitalizations
- 8: Residential Placement
- 9: Number of Current Health Care Providers
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- 13: Child Behavior Check List (CBCL)
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The data will be de-identified. The data will exist only within a password encrypted file which is only accessible by the PIs of this study. The data will be destroyed one year after successful completion of the study.

1. Risks & Benefits
 - a. What are the risks and what will be done to monitor the risks?
No Risks
 - b. What is the likelihood of each risk (common, likely, infrequent, or rare)?

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Potential Risks

- Participation in this study poses a risk for breach of confidentiality. RARE

What will be done to reduce or monitor these risks?

- To minimize the breach of confidentiality risk, we will only use the data identified above and this will be stored according to approved procedures and destroyed one-year after completion of the study.

c. What are the benefits?

iii. To the individual

Other than participation in the CAPES program, there will be no direct benefits to the study participants. The knowledge and insights emanating from this study will potentially advance efforts surrounding coordinated care and ultimately may lead to better care for families with children/adolescents who have two or more serious issues.

iv. To society

The utilization of a collaborative care service delivery model which demonstrates clinical efficacy.

1. Statistical Design

It is hypothesized that the effectiveness of the CAPES program will result in statistically lower post-test scores on the measurement instruments and utilization metrics. After describing the study population with descriptive statistics, the t-test for dependent samples will be utilized to determine if there are statistically significant differences in pre-test scores and post-test scores, and utilization metrics, after six months of participation in the CAPES program.

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