Family Caregiver Wants and Needs
as Related to Hopefulness and Problem Severity

A Senior Honors Thesis

Presented in Partial Fulfillment of the Requirements for Graduation with Research Distinction in Psychology in the Undergraduate Colleges of The Ohio State University

By

Alexandria Y. Lammers

The Ohio State University

June, 2007

Project Advisors: Dr. Mary A. Fristad, Departments of Psychology and Psychiatry

and

Dr. Stephen Gavazzi, Department of Human Development and Family Science
Abstract

This study was completed as part of the Family and Systems Team (FAST) evaluation project conducted in the state of Ohio. The Family Caregiver Wants and Needs Scale (FCWNS) was utilized to investigate the relationship between how hopeful a family feels when they begin to use mental healthcare services for their child and how empowered they perceive themselves to be at that time, as well as the relationship hopefulness and empowerment have with the child’s problem severity. Although the FCWNS had not undergone previous psychometric scrutiny, internal reliability for the Family Caregiver Wants and Needs Scale was predicted and found. I hypothesized a family’s level of hopefulness would be highly positively correlated with their level of caregiver empowerment when services were initiated. Additionally, I expected the child’s level of problem severity to be negatively correlated with levels of hopefulness and empowerment, so a child would be perceived as having less problem severity if their caregiver experienced more hopefulness and empowerment. Hopefulness and problem severity were correlated. Empowerment in general was not correlated with any hypothesized variables. Factor analysis of FCWNS items indicated there were two clusters; healthcare related empowerment items and social support related items. The healthcare empowerment items were correlated with hopefulness and problem severity. This study has broad implications for parent advocates and for programs designed to link youth in serious need with appropriate behavioral and mental health services by creating a more comprehensive way to evaluate their families.
Introduction

Empowerment is a term defined in many different ways. However, there is general agreement that in a broad sense of the word, empowerment is the outcome of any process that enables people to gain control of their lives (Heflinger & Bickman, 1997; Man, Lam, & Bard, 2003; Singh, & Curtis, 1997). When discussed in the field of mental health, such processes usually provide people with knowledge of the mental health services system, coping skills for daily life, and social support from various members of the community to manage their lives (Koren, DeChillo, & Friesen, 1992; Heflinger & Bickman, 1997; Langford, Bowsher, Maloney, & Lillis, 1997; Man et al., 2003; Singh & Curtis, 1997). Historically, children and individuals with mental illness have not been empowered and they have had difficulty finding appropriate services. Therefore, attention should be given to empowering the entire family or whomever is responsible for accessing services on the child’s behalf (Singh & Curtis, 1997). The term “caregiver empowerment” will be used to refer to this specific form of empowerment for the purposes of this study.

Recently, parent advocacy has emerged as one way to aid a child through aiding the family. This idea is derived from Bronfenbrenner’s social-ecological theory, which acknowledges the family’s position as a liaison between the child and the service system (Bronfenbrenner, 1979; Heflinger & Bickman, 1997). Parent advocacy is the act of supplying parents with the ability to use and/or change services given to their child to use how they best see fit. When done correctly, caregiver empowerment is the outcome.
Several different instruments have been developed to measure how empowered persons perceive themselves to be. The current study utilizes the Family Caregiver Wants and Needs Scale (FCWNS) (Goldberg-Arnold, Fristad & Gavazzi, 1999), a scale already in use by the State of Ohio for the Family and Systems Team (FAST) project, which is an outcome evaluation effort. While little research has been conducted on the FCWNS, its item content is similar to other caregiver empowerment scales, including the Family Empowerment Scale (FES) (Koren et al., 1992) and the Family Empowerment Questionnaire (FEQ) (Man et al., 2003).

The FES (Koren et al., 1992) measures empowerment in three areas, including family, service system, and community. The family area refers to the family caregiver’s ability to manage daily situations in the home. The service system area assesses the caregiver’s ability to work with the service system to obtain necessary services for his or her child, and lastly, the community area assesses caregivers’ advocacy to change services for all children, not just their own. For example, will the changes they cause be long-lasting enough to impact children who come through the behavioral health care system in the future? This scale focuses heavily on how the family understands and is able to use the service system.

The Family Empowerment Questionnaire (FEQ) (Man et al., 2003) was developed to measure the level of empowerment in families after a family member had undergone surgery. The FEQ is pertinent because it focuses on many of the same concerns as caregiver empowerment; the four sub-domains are knowledge, skill, support, and aspiration. The FEQ asks caregivers about the extent of their knowledge of
the mental health system, their skill at coping with the situation, the level of support they receive from others, as well as their level of aspiration and motivation to succeed.

Both the FES and FEQ measure basic principles of caregiver empowerment: knowledge of the mental health service system, coping skills, and social support. These measures are similar to the FCWNS’s focus on whether the caregiver has been given a “voice and choice” in their child’s behavioral healthcare. Singh & Curtis (1997) found demographic correlates to the FES, and concluded caregiver empowerment is related to participation in parent support groups, caregiver gender, and education level of the caregiver.

Research on hopefulness has linked it to ideas of empowerment. While a vague term in practice, it generally carries broad ideas of a positive future, a sense of ability, and having a purpose in life (Bland, & Darlington, 2002). One of the more important findings that relates hopefulness and empowerment is Brackney and Westman’s (1992) research which associates hope with an internal locus of control. In regard to positive events, an internal locus of control in life implies many of the same beliefs and feelings that empowerment does. They both involve the belief that the individual is capable of caring for him or herself, and of controlling his or her own life. Therefore, it would follow that hopefulness is positively correlated with empowerment. A second way to consider the relationship between hopefulness and empowerment is to consider empowerment a potent form of hopefulness. This would essentially make empowerment a type of hopefulness, which would imply an even greater correlation between the two.

Ultimately, the purpose of empowerment and hopefulness is to help reduce the severity of the course of the illness experienced. For the purposes of this paper,
problem severity refers to the level of the youth’s mental health issues and/or alcohol or drug issues. Since the term ‘problem severity’ is a more straight-forward concept when compared to empowerment or hopefulness, research on problem severity can focus on the most effective means of reducing it. Regarding youth with behavioral and emotional disturbances, some have suggested that greater caregiver empowerment leads to increased involvement in the child’s mental health care, which can improve the quality of services that child receives, which eventually decreases the level of the child’s problem severity (Bickman, Heflinger, Northrup, Sonnichsen and Schilling, 1998).

Problem severity is also associated with who receives services and/or treatment. One study of adults in inpatient and outpatient settings found that services were more likely to be given to those who had especially high problem severity, and were also more likely to occur if the patient’s needs were in the family assistance, medical or psychological areas (Asche & Harrison, 2002).

Problem severity, empowerment and hopefulness are all incorporated into the Phase Model, which provides a theory integrating these three concepts in relation to psychotherapy outcomes (Howard, Lueger, Maling & Martinovich, 1993). While this model is directly concerned with therapy, the goal of treating an individual to reduce their problem severity is shared with parent advocacy, so it is plausible to consider the outcomes occurring in a similar manner. Howard et al. (1993) suggest that improvement happens in three stages: remoralization, remediation, and rehabilitation. Remoralization translates directly into the re-building of an individual’s hopefulness, and remediation refers to reduction in problem severity. Rehabilitation is in reference to improvement in life-functioning. Another pertinent reason to use the Phase Model as our theoretical
background is because it was utilized during the creation of the Ohio Scales (Ogles, Dowell, Hatfield, Melendez & Carlston, 2004), from which this study draws its measures for hopefulness and problem severity.

This study seeks to determine correlates of caregiver empowerment. However, psychometric testing of the FCWNS is also important, so the first hypothesis is that there will be internal reliability of the FCWNS. Second, it is hypothesized that a family’s level of hopefulness will be highly positively correlated with their level of caregiver empowerment when services are initiated, as empowerment can be viewed as an enhanced form of hopefulness. The third hypothesis predicts that the caregiver’s level of hopefulness is negatively correlated with the perceive level of the child’s problem severity, while the fourth hypothesis predicts empowerment will be negatively correlated with problem severity. Together this means that when a caregiver experiences greater hopefulness and empowerment, they will observe less problem severity in the child.

![Diagram of hypotheses](image)

**Fig. 1.** Model of hypotheses for the FAST data
The model for these predictions illustrates the possibility that greater hopefulness could lead to greater empowerment, since there should not be elevated levels of empowerment without hopefulness if empowerment is viewed as an advanced form of hopefulness. The relationship between hopefulness and problem severity is in agreement with the Phase Model, which predicts the greatest amount of reduction in problem severity when there are higher levels of hopefulness (Howard et al., 1993). If, indeed empowerment can be thought of as the high-end of hopefulness, then it may also be able to predict a reduction of problem severity.

Hypotheses:

1. There is internal reliability within the FCWNS.
2. Hopefulness and empowerment are positively correlated.
3. Hopefulness and problem severity are negatively correlated.
4. Empowerment and problem severity are negatively correlated.
Method

Participants

This study was conducted as part of the FAST Project. FAST was a response to increased awareness of parents relinquishing custody of their children to the state so their children could receive behavioral healthcare. To counter this problem, the FAST program was created to help all 88 Ohio counties aid youth at risk of placement. The focus of FAST is to provide families with non-traditional services while requiring counties to offer parent advocates to these families, whether or not parent advocates are ultimately used. To receive these non-traditional services, youth must remain in the home (i.e., FAST would not fund out-of-home placements) and services must be non-Medicaid reimbursable. Some examples of services provided via FAST include transportation, animal therapy, art therapy, camps, mentors, tutoring, and music programs. In addition, FAST has a stringent evaluation component to assess if and how the program is working county by county.

This study utilized data from the FAST 05 year. In 2005, demographics were only collected about the involved youth, while none were collected about their caregivers. In all, there were roughly 2500 youth served by FAST 05. Of this group, only 545 had complete enrollment forms, a necessity for this study. Furthermore, of the 545 youth, only 119 also had complete termination forms as of the beginning of this study. Ultimately, the participants were 118 caregivers of youth enrolled in FAST who had completed the Family Caregiver Wants and Needs Scale and the Ohio Scales at enrollment (Time 1, T1) and termination (Time 2, T2). It was later decided to use only data from T1, but instead of increasing the sample size to 545 the participant group of
118 remained. One potentially qualified participant was eliminated as his/her child’s race was not specified, and the decision was made against having a racial category of one.

A majority of participants had offspring who were Caucasian (84%), the remainder (16%) were African-American. Most offspring were male (66%). Their average age was 12.2 years (range, 4 to 17.6 years). Youth required services because of mental health related issues (88%), alcohol or other drug issues (2%), or dual-diagnoses (i.e., mental health and alcohol or other drug issues, 10%) (Center for Family Research [CFR], 2005).

**Questionnaires**

*Empowerment.* The Family Caregiver Wants and Needs Scale (FCWNS) was developed by Goldberg-Arnold, Fristad and Gavazzi (1999). It is based on several constructs noted in their early work with family psychoeducation, a type of advocacy (Goldberg-Arnold, Fristad & Gavazzi, 1999). There are 13 items in this scale, which ask how frequently the informant has had contact with individuals or situations. Items are rated on a scale of 0-5, with 0 being “never” and 5 being “always.” The overall score for the instrument ranges from 0-65, with 0 representing a low amount of caregiver empowerment and 65 representing a high amount of caregiver empowerment. The scale measures empowerment via an assessment of the family caregiver’s access to health care professionals who are supportive and do not blame the caregiver for the child’s issue(s). Additional items are designed to report whether or not caregivers feel they have been given a voice in the process by the health care professional. A sample question from this scale asks if the caregiver has recently had “A physician or other
health care professional who seemed to believe there is something medically wrong with your child?” (See Appendix A for the full scale.) There is no published research on the validity or reliability of the FCWNS as a measure of empowerment, although it has a reasonable level of face validity.

Hopefulness. The Ohio Scales are a set of evaluations used by the state, and administered to people with mental health issues. They were developed by Ogles, Melendez, Davis, and Lunnen (1999), and the Ohio Department of Mental Health mandates their use for youth clients who access services from the state. The Ohio Scales have three versions, one for the youth, one for their parent or primary caregiver, and one for the youth’s agency worker; the parent scales were analyzed in this study so the same informant would complete the FCWNS and the Ohio Scales. The Ohio Scales have four sub-scales that measure problem severity, functioning, satisfaction, and hopefulness. This study utilized the hopefulness and problem severity sub-scales.

The hopefulness sub-scale has been shown to have a two-week test-retest reliability of .79 (Ogles et al., 2004). Internal consistency, measured by Chronbach’s alpha, averaged across a community and clinical sample, is .77. One item from this sub-scale poses the question, “How capable of dealing with your child’s problems do you feel right now?” (See Appendix C for the full scale.) Each of the four questions is rated on a one to six scale, with one indicating greater hope and six indicating very little hope. Scores for this sub-scale range from 4 to 24, higher scores indicate less hope. The mean and standard deviation for a clinical sample are 13.81 and 5.26, respectively, while the community sample had a mean of 8.31 and a standard deviation of 3.52.
(Ogles et al., 2004), suggesting the sub-scale is sensitive enough to discriminate between a community and a clinical sample.

**Problem Severity.** The child’s problem severity was assessed using the 20-item parent-reported problem severity sub-scale of the Ohio Scales (Ogles et al., 1999). This sub-scale assesses some common problems of youth who receive behavioral healthcare. Factor analyses indicate the parent rated problem severity subscale measures three clusters: externalizing, internalizing, and delinquency (Ogles et al., 2004). Externalizing questions ask about the youth’s interactions with others, and are represented by items 1-6 and 10-11. An example of an externalizing item is how frequently the youth is “yelling, swearing, or screaming at others” (See Appendix B for the full scale). Internalizing problems are assessed via items 12-20; they focus on the youth’s behavior toward him or herself. One question, for example, asks if the child is “hurting [his or her] self (cutting or scratching self, taking pills).” Lastly, delinquency questions focus on the youth’s relationship with the law, and constitute items 7-9. A sample question is how frequently the youth is “breaking rules or breaking the law (out past curfew, stealing).”

All the items are measured on a six-point Likert-type scale ranging from 0 “not at all” to 5 “all the time.” The scale’s range is from 0-100, with lower scores indicating less problem severity. Internal consistency for the parent version of this measure is .91, while the two-week test-retest reliability is .88. The parent version has higher internal consistency than the agency worker version (.86), making it more reliable for use in this study.
Procedure

Data were collected from all 88 Ohio counties. To ensure a complete dataset, the 2005 FAST dataset was used.

Results

Examination of the Dataset

Prior to conducting analyses, the potential impact of the youths' age, race and gender on scale scores was examined. Despite an age range of 4 to 17.6 years, there was no correlation between age and any of the constructs. There was also no difference in scores between males and females or between Caucasian and African-American youth (see Table 1).

Table 1

Demographic Means and Standard Deviations for Construct Scales

<table>
<thead>
<tr>
<th>Scale Statistics</th>
<th>Male</th>
<th>Female</th>
<th>Caucasian</th>
<th>African-American</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hopefulness</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>13.65</td>
<td>12.48</td>
<td>12.92</td>
<td>15.00</td>
</tr>
<tr>
<td>SD</td>
<td>4.66</td>
<td>4.34</td>
<td>4.39</td>
<td>5.16</td>
</tr>
<tr>
<td>Empowerment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>43.88</td>
<td>43.00</td>
<td>43.62</td>
<td>43.36</td>
</tr>
<tr>
<td>SD</td>
<td>16.06</td>
<td>13.69</td>
<td>15.51</td>
<td>14.17</td>
</tr>
<tr>
<td>Problem Severity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M</td>
<td>29.71</td>
<td>28.73</td>
<td>29.44</td>
<td>29.00</td>
</tr>
<tr>
<td>SD</td>
<td>14.74</td>
<td>16.04</td>
<td>15.75</td>
<td>11.74</td>
</tr>
</tbody>
</table>
Hypothesis Testing

To determine if the FCWNS had internal reliability, Chronbach’s alpha was calculated for this scale. The value was .918, indicating strong internal reliability and support for the first hypothesis.

When discussing the correlations of the constructs, it is the levels of the constructs perceived by the caregiver that will be referred to rather than the scores of the instruments. This was the original intent of the hypotheses.

Hypothesis 2 anticipated levels of hopefulness and empowerment would be positively correlated (i.e., more hopefulness perceived by the caregiver would be associated with more empowerment in the caregiver, and vice versa). Pearson correlation coefficients were calculated to test hypothesis two, three and four (see Table 2). Hopefulness and empowerment were not significantly related, not supporting hypothesis two.

Hypothesis 3 anticipated levels of hopefulness and problem severity would be negatively correlated. Hopefulness and problem severity perceived by the caregiver were moderately correlated (r = -0.539, p<.05), indicating less hopefulness is associated with higher problem severity. Thus, hypothesis three was supported.

Hypothesis 4 anticipated empowerment and problem severity would be negatively correlated, suggesting more empowerment would generally be found in families whose children had lower levels of problem. Empowerment and problem severity were not significantly related, thus, hypothesis four was not supported.

Interestingly, while exploring the lack of significant relationships between empowerment and the other two constructs, it was found through factor analysis that
FCWNS items separate into two categories; items 1-3 comprise the first cluster, and are referred to as healthcare empowerment. Items 4-13 constitute the second cluster, termed social empowerment. Table 2 shows the breakdown of all the FCWNS items.

<table>
<thead>
<tr>
<th>Table 2: Factor Analysis Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Component</td>
</tr>
<tr>
<td>intBelievesMedicalProblem</td>
</tr>
<tr>
<td>intResponsiveQuestions</td>
</tr>
<tr>
<td>intNoBlame</td>
</tr>
<tr>
<td>intUnderstandsPOV</td>
</tr>
<tr>
<td>intProvidedResources</td>
</tr>
<tr>
<td>intGaveTips</td>
</tr>
<tr>
<td>intAssistingServices</td>
</tr>
<tr>
<td>intHelpDeal</td>
</tr>
<tr>
<td>intFamilyNeeds</td>
</tr>
<tr>
<td>intNotAlone</td>
</tr>
<tr>
<td>intValuesCulture</td>
</tr>
<tr>
<td>intNeedsConsidered</td>
</tr>
<tr>
<td>intPlanningInfluence</td>
</tr>
</tbody>
</table>

While empowerment as a whole was not related to either hopefulness or problem severity, healthcare empowerment was correlated with each (hopefulness scores, r= -0.233, p= 0.01; problem severity scores, r= 0.227, p=0.01) (See Table 3).
Table 3: Pearson Correlations of the Construct Levels

<table>
<thead>
<tr>
<th></th>
<th>Hopefulness</th>
<th>Problem Severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hopefulness</td>
<td>---</td>
<td>-0.539**</td>
</tr>
<tr>
<td>Problem Severity</td>
<td>-0.539**</td>
<td>---</td>
</tr>
<tr>
<td>Empowerment</td>
<td>0.024</td>
<td>0.036</td>
</tr>
<tr>
<td>Healthcare</td>
<td>-0.233*</td>
<td>0.227*</td>
</tr>
<tr>
<td>Healthcare</td>
<td>0.117</td>
<td>-0.042</td>
</tr>
<tr>
<td>Empowerment</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**. Significant at the 0.01 level
*. Significant at the 0.05 level

This means less hopefulness and greater problem severity are associated with greater levels of healthcare empowerment, as indicated by the caregiver, and vice versa. Thus, the suggested model adapted from the Phase Model was not supported by this study (See Figure 3). Figure 4 is a derivation of Figure 3, in which the construct empowerment is replaced by healthcare empowerment, to more clearly demonstrate the strengths of relationships between healthcare empowerment and the other constructs.

**. Significant at the 0.01 level
*. Significant at the 0.05 level

**Fig. 3. Correlations of the Levels of the Constructs**
Discussion

The negative correlation between hopefulness and problem severity levels seems intuitive; it makes sense for caregivers to be less hopeful when they perceive their children to have many problems. But what caused healthcare empowerment to behave in the opposite direction towards hopefulness and problem severity as predicted, while empowerment as a whole and social empowerment had no relation to either of the constructs? The more fitting question may be, what is the importance of items on the FCWNS that broke down into these two clusters?

The items in the healthcare empowerment category are unified because they all mention an aspect of the healthcare system, such as medication or a healthcare professional. Items in the social empowerment category are connected because the resources and information these questions ask about could all be provided to the caregiver by his or her regular social network, and would not necessarily require access to mental healthcare. It is plausible that caregivers value information from these two groups differently, and hence they would be affected differently, too. For example, a
caregiver could hear a neighbor and a physician both say, “I believe your child has a legitimate mental healthcare problem,” and interpret the same sentence in separate ways. From the physician, this comment might help validate some of the caregiver’s concerns, whereas the neighbors comment might seem like a judgment to the caregiver. Another possibility is that healthcare empowerment items are most accurately measuring the level of access a caregiver has to appropriate mental healthcare for their child, instead of the level of caregiver empowerment. This would make the healthcare empowerment cluster similar to the service system are of Koren et al.’s FES (1992).

From this perspective, the negative correlation between the level of healthcare empowerment and the level hopefulness as well as the positive correlation between healthcare empowerment and problem severity does not appear as surprising. By the time caregivers have access to mental healthcare and find a professional who believes the youth has real problems the symptoms have become severe, whereas a caregiver can receive support from a social network regardless of problems their child may have. There is also the mentality that people should not go to a doctor until they are sick, which hinders early prevention services, so there is a decreased likelihood for a child to see a doctor when there problems are not severe. As Singh & Curtis (1997) found in their work, patients were more likely to receive treatment when there was high problem severity. The result is that access to behavioral healthcare is positively correlated with problem severity of the youth. In other words, as problem severity increases, so does access to mental healthcare, and when there is less problem severity, there is less access to mental healthcare.
Furthermore, a caregiver may have a high amount of hope for the future when their child’s problem severity is low, but as problem severity climbs, the caregiver may grow progressively less hopeful. One reason a child’s level of problem severity may rise unchecked is because adequate behavioral healthcare cannot be found. So, by the time the necessary help is found, the situation is already out of control, and the caregiver has lost hope. This is one possible explanation for the negative correlation between hopefulness and problem severity, but if it is happening it shows a problem with the mental healthcare system as a whole. If the previous situations are true, perhaps more focus should be given to recognizing symptoms in youth with mental health or alcohol and drug related issues, and getting the care they need before their situations become too severe.

Another interpretation of the data is more optimistic. Focusing on the positive correlation between problem severity and healthcare empowerment, youth with a high level of problem severity also have a high level of healthcare empowerment. This may mean that youth who need access to mental healthcare are receiving it, while youth who do not have a high degree of problem severity and who therefore do not need access to mental healthcare, are receiving less treatment. In this light, the mental healthcare system is seeing exactly who needs to be treated, and they are not wasting their time with those who do not. It is still important to find out if this situation is true, because it would be beneficial to look at what the mental healthcare system is doing right in these cases, in order to replicate it elsewhere.

While this study has shown that the FCWNS has very strong internal reliability, one limitation of this study is that validity for the FCWNS was not tested. Specifically,
determining whether the FCWNS has adequate construct validity would help determine whether the FCWNS measures caregiver empowerment or access to behavioral healthcare and social support.

A second limitation of this study is the exclusive use of baseline data. If follow-up data were available for analysis, more could be learned about the quality and impact of services received. A third limitation is that demographic data is not collected about the caregivers, only for the youth. Access to the caregivers’ race, age, level of education and gender would allow for the examination these variables in relation to empowerment, hopefulness and problem severity, especially given Singh & Curtis’ (1997) findings mentioned earlier.

The final and most important limitation of this study is that it is correlational. Thus, directionality of relationships cannot be determined. A natural next step would be to repeat this study and use the termination data in addition to the enrollment data already in use, to test for causal relationships between the constructs.

Also, determining the correlation between empowerment and the different clusters of problem severity (internalizing, externalizing and delinquency) might reveal relationships between these variables.


problems, functioning and satisfaction scales (short form) user’s manual.

Columbus, OH: Ohio Department of Mental Health, Office of Program Evaluation
and Research.

Patterson, Bank, & Stoolmiller (1990). The preadolescent’s contributions to disrupted
family process. In R. Montemayor, G.R. Adams & T.P. Gullotta (Eds.), From

have serious emotional disturbance and attention-deficit/hyperactivity disorder.

Appendix A

Empowerment Scale

Family Caregiver Wants and Needs PRE-Scale (FCWNS)

Youth MACSIS # ________________ County ________________

In the last six months, how often have you had contact with the kinds of individuals or have experienced the kinds of situations described below:

<table>
<thead>
<tr>
<th>Always</th>
<th>Almost Always</th>
<th>Frequently</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

1. A physician or other health care professional who seemed to believe there is something medically wrong with your child?
2. Someone who was responsive to your questions and concerns about medications for your child?
3. A mental health professional who did not blame you for causing your child's problems?
4. Someone who seemed to "understand your point of view" in dealing with problems and concerns arising from services or treatment for your child?
5. Resources that have provided you with helpful information on how to deal with your child's problems?
6. Someone who gave you "tips" about getting your child the help they need?
7. Services that could assist you in helping your child?
8. Someone who helped you deal with the stigma of having a child with difficulties?
9. Support that meets my family's needs?
10. Someone who made you feel you are not alone?

In the last six months, to what extent:

11. Were your family's values and culture taken into account when planning for your child?
12. Were the needs/circumstances of your family considered in this planning?
13. Were you able to influence planning for your child's treatment or services?

Revised 6/20/06
## Appendix B

### Problem Severity Scale

**Ohio Mental Health Consumer Outcomes System**

**Ohio Youth Problem, Functioning, and Satisfaction Scales**

**Parent Rating – Short Form**

<table>
<thead>
<tr>
<th>Instructions: Please rate the degree to which your child has experienced the following problems in the past 30 days.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Not at All</strong></td>
</tr>
<tr>
<td>1. Arguing with others</td>
</tr>
<tr>
<td>2. Getting into fights</td>
</tr>
<tr>
<td>3. Yelling, swearing, or screaming at others</td>
</tr>
<tr>
<td>4. Fits of anger</td>
</tr>
<tr>
<td>5. Refusing to do things teachers or parents ask</td>
</tr>
<tr>
<td>6. Causing trouble for no reason</td>
</tr>
<tr>
<td>7. Using drugs or alcohol</td>
</tr>
<tr>
<td>8. Breaking rules or breaking the law (out past curfew, stealing)</td>
</tr>
<tr>
<td>9. Skipping school or classes</td>
</tr>
<tr>
<td>10. Lying</td>
</tr>
<tr>
<td>11. Can’t seem to sit still, having too much energy</td>
</tr>
<tr>
<td>12. Hurting self (cutting or scratching self, taking pills)</td>
</tr>
<tr>
<td>13. Talking or thinking about death</td>
</tr>
<tr>
<td>14. Feeling worthless or useless</td>
</tr>
<tr>
<td>15. Feeling lonely and having no friends</td>
</tr>
<tr>
<td>16. Feeling anxious or fearful</td>
</tr>
<tr>
<td>17. Worrying that something bad is going to happen</td>
</tr>
<tr>
<td>18. Feeling sad or depressed</td>
</tr>
<tr>
<td>19. Nightmares</td>
</tr>
<tr>
<td>20. Eating problems</td>
</tr>
</tbody>
</table>

(Add ratings together) Total ________
Appendix C

Hopefulness Scale

Ohio Mental Health Consumer Outcomes System
Ohio Youth Problem, Functioning, and Satisfaction Scales

Parent Rating – Short Form

Instructions: Please circle your response to each question.

1. Overall, how satisfied are you with your relationship with your child right now?
   1. Extremely satisfied
   2. Moderately satisfied
   3. Somewhat satisfied
   4. Somewhat dissatisfied
   5. Moderately dissatisfied
   6. Extremely dissatisfied

2. How capable of dealing with your child’s problems do you feel right now?
   1. Extremely capable
   2. Moderately capable
   3. Somewhat capable
   4. Somewhat incapable
   5. Moderately incapable
   6. Extremely incapable

3. How much stress or pressure is in your life right now?
   1. Very little
   2. Some
   3. Quite a bit
   4. A moderate amount
   5. A great deal
   6. Unbearable amounts

4. How optimistic are you about your child’s future right now?
   1. The future looks very bright
   2. The future looks somewhat bright
   3. The future looks OK
   4. The future looks both good and bad
   5. The future looks bad
   6. The future looks very bad

Total: _______