Refinement of an Instrument to Measure Mental Health Literacy and Examination of Interventions to Enhance Mental Health Literacy

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There is a growing consensus about the importance of involving mental health care consumers in making decisions about their health care. This is a challenge, however, for those who cannot effectively understand health information. Research has shown that poor health literacy results in poor health outcomes and higher costs. Mental healthcare consumers and caregivers of children with mental illness and SED (Serious Emotional Disturbances), especially struggle with navigating complex systems and interactions with their and their children’s mental health care providers.

In this paper, we report on our continued refinement of an instrument to measure mental health literacy among caregivers of children with SED and their providers. We also report on a qualitative study to design message interventions to improve and enhance mental health literacy among caregivers and providers.

Results of the study suggest that three sub-domains, Family Agency, Knowledge and Capability, and Belief in Control may determine mental health literacy. These sub domains show moderate to high internal reliability and evidence of validity when tested on a sample of 175 caregivers. Further analysis suggests a complex relationship between mental health literacy among caregivers and their providers. Both groups consider a belief in the family’s agency (the right and ability to control their own destiny) the highest of all sub-domains; and both rated their own communication behaviors and knowledge moderately among all sub-domains. The results associated with “Knowledge and Competency” are consistent with previous research. The results suggest a positive relationship between provider and caregiver mental health literacy. However, mental health literacy appears to be a complex concept, with some aspects of caregiver literacy (Belief in Control), negatively related to provider literacy.

Finally, an investigation of message-interventions to raise literacy among providers and caregivers’ communications was conducted through focus groups with caregivers and providers. Results suggest that multiple information sources are needed to enhance caregiver literacy, and that different aspects of literacy may be best delivered using different information channels. Simple messages may be best disseminated through posters or brochures, such as messages regarding caregiver rights and the importance of caregivers’ opinions. Other messages may be best disseminated through channels such as DVDs. These messages might include where to obtain services and how to receive testing for a child. Finally, complex messages, such as how to balance the risks and benefits of medication, and how to make placement decisions for a child, may involve teaching caregivers decision-making or other complex skills and should be conveyed through techniques such as one-on-one counseling, training, or coaching.
Background

Among the many ways health care service and delivery has changed in recent years, perhaps one of the most important is the evolving role of the patient-consumer. Developments in medicine and information technology, as well as the long-term, chronic nature of many diseases (e.g., hypertension, asthma, diabetes), have increased concerns for improving the capacity of consumers to be better informed and educated about their health conditions. The core of this capacity is the concept of health literacy. Health literacy has been defined as both the ability to read, write, and comprehend words and phrases (Nutbeam, 2000; Parker, 2000; DeWalt et al., 2004) as well as the ability and knowledge to use health and medical information to promote and maintain physical health (DeWalt et al., 2004; Jorm, 2000; Nutbeam, 2000; Parker, 2000; Parker, Ratzan, & Lurie, 2003; Parker & Gazmararian, 2003; Watters, 2003). The heightened attention to the role of consumer health literacy and knowledge is reflected in the specific objectives of Healthy People 2010, a campaign to elevate the health status of Americans by the end of the decade (U.S. Department of Health and Human Services, 2000).

Parallel to the development of health literacy is the concept of mental health literacy. There is a growing consensus on the importance of involving consumers in making decisions about their own mental health care (World Health Organization, 1990). Mental health literacy is a core component of meaningful consumer involvement. Mental health literacy is typically defined as knowledge and beliefs about mental disorders coupled with the ability to access, understand, and use information to recognize and manage disorders (Lauber et al., 2003). Behavioral or mental health literacy definitions have also included factors such as knowledge about mental disorders; beliefs and attitudes about mental disorders that promote appropriate help-seeking; the ability to recognize specific disorders; knowledge of how to obtain mental health information and treatment; and knowledge of risk factors, causes, and treatment of mental disorders (Fisher & Goldney, 2003; Jorm et al., 1997; Lauber et al., 2005; Marie, Forsyth, & Miles, 2004). Thus, in addition to looking at functional, interactive, and critical dimensions of literacy, the definition of mental health literacy also acknowledges the role that beliefs play in the recognition, prevention, and management of mental disorders (Goldney et al., 2002). Parlslow and Jorm (2002) suggest adopting a model that acknowledges the role of knowledge, beliefs, and attitudes in reinforcing and enabling health-related behaviors.

Recent surveys, however, indicate that large segments of the public have low mental health literacy, reflected in a lack of knowledge about symptoms of mental disorders, meanings of psychiatric terms, and the effectiveness of various modes of treatment (Jorm, 2000). In addition, little research has been conducted to date on mental health literacy among caregivers of children with severe emotional disturbance (SED), emotional or behavioral disorders (EBD), or mental illness. No instrument has been developed to measure mental health literacy among caregivers or providers of services for children with SED. However, almost 7 million children between 9 and 17 years old are confronted with SED (Faenza & Steel, 1999; Halfon & Newacheck, 1999). Thus, the implications of low mental health literacy in the area of children’s mental health are not likely to be insubstantial.
Availability and Sources of Health Information

Further complicating health and mental health literacy are the issues of source and availability of information. Health information must be provided in a format that can be easily understood and utilized by the consumer. More health information is available than ever before, such as on the Internet and in other computer-based programs that offer great opportunities for developing health literacy (Christensen & Griffiths, 2000). The ready access to information can be empowering, but only if healthcare consumers can read, understand, and apply it (Weaver, 2003).

Christensen and Griffiths (2000) report that there are two factors related to health information obtained on the web that determine whether a person can utilize the information: quality of the information and the amount of the information available (e.g., the amount of information overload experienced by the information user). The implications are that high-quality and accurate information must be readily available to consumers (Parlslow & Jorm, 2002), and that consumers must be able to understand and discern it before it is useful to them (Stephenson, Green, Wallace, Earl, Orieck & Taylor, 2004). In fact, an audit of popular websites addressing depression, for example, reveals that many Internet resources are unbalanced and contain misinformation (Christensen & Griffiths, 2000).

The problem of low health literacy is further complicated by the sophisticated nature of many health-related materials intended for the average American public. Cotuga, Vickery and Carpenter-Haefele (2005) analyzed the reading levels of the patient education materials included in health care journals. Of the ten-document sample evaluated, only two fell within the recommended 5th-6th grade reading level, and five measured above the 8th-9th grade reading level, the estimated mean reading level of the United States population. Health literacy in health information is related to both the reading level of the text and to other variables as well, and must be seen by the patient as being relevant to his/her concerns (Use proven strategies, 2005).

A third issue associated with the ability to use information has to do with the number of cues that are provided through a particular media channel. Rich media channels provide cues from multiple sources, while lean channels provide few cues. For example, face-to-face communication is considered to be the richest channel because it provides communication cues via sight and sound, and allows for two-way synchronous communication. E-mail is considered to be a lean channel because it provides only visual cues and only allows for asynchronous communication (Daft & Lengel, 1984; Dennis & Kinney, 1998). The type of task is believed to determine the best choice of media source. Equivocal (vague or ambiguous) messages need richer media, and nonequivocal (clearer) messages are best served by leaner media. If communicators are unclear about something, or do not understand it, a richer medium allows them to ask questions and obtain answers as they arise, and allows them to use as many cues (body language, voice, tone, etc.) as possible. A richer medium also allows for communicator flexibility and the ability to show feelings (D’Ambra, Rice, & O’Connor, 1998).

For example, a study looking at the choice of media for an employee benefits message found that a combination of print materials and on-line information appeared to be the universal preference for explaining basic information and factors that could affect decision-making. For communication assisting employees in their decision-making, one-on-one counseling (in person or via a hotline) was recommended (Freitag & Picherit-Duthler, 2008).
Health Literacy and Communication Competence

A final component of health literacy for both healthcare consumers and providers is communication competence. The concept of communication competence has been defined as “the perceived ability to communicate one’s view as well as to understand another’s perspective across a variety of situations” (Query & James, 1989, p.171). As Cegala, Socha McGee, and McNeilis (1996), McNeilis (2001), and Query and James (1989) point out, communication competence is bound by context, situation, and goals. A competent communicator “fulfills personal goals or communicative functions” in a way that is both appropriate and effective (Cupach & Spitzberg, 1983, p. 365).

In a communication competence model of patient-provider interactions, both doctors and patients have variable levels of competence. Cegala, McNeilis, Socha McGee, and Jonas (1995) measured the communication competence of doctors on two related dimensions, relational communication and informative communication. Doctors’ communication competence is related to their information-providing behaviors. Competent physicians provided both relational communication by providing explanations to patients about diagnosis, treatment options, and prognosis, and by explaining technical information, and provided informative communication by providing information about the medical problem and verifying the patient’s understanding. Doctors’ communication competence was also related to their ability to demonstrate open and friendly communication, and their ability to “establish a warm, friendly, trusting environment; convey care, interest, and concern for the patient; demonstrate affective support, such as sympathy and empathy and be responsive to patients’ needs and concerns” (Cegala et al., 1996, p. 11, 18).

Patients’ communication competence is related to their ability to prepare for the medical interview, be knowledgeable about their illness, provide information about symptoms, ask questions and actively seek information, and stay on topic (Cegala et al., 1996; Cegala, Gade, Lenzmeier Broz and McClure, 2004).

Research to Date

Based on the research cited and the need for a measure of mental health literacy for caregivers of children with SED, Smith, Armstrong, & Davis (2006) conducted a review of the literature that identified variables and concepts of mental health consumer knowledge, understanding, comprehension, and empowerment. This list of variables was then refined through eight focus groups in Hillsborough County, Florida with mental health care consumers, caregivers of children with SED, and mental health care providers. The focus group research, combined with the content analysis, yielded a list of mental health knowledge and literacy variables. These variables were combined and refined to draft two instruments to measure caregiver and provider mental health literacy for children with SED.

A caregiver instrument was drafted that included 68 items on a 5-point Likert scale (ranging from Agree Strongly to Disagree Strongly). Also included was an additional scale called “Factual Knowledge” that was composed of 10 true/false statements testing factual knowledge of mental health information. The caregiver instrument included seven domains:
• Belief in Capabilities (10 questions)
• Belief in Rights (9)
• Belief in Own Value (5)
• Knowledge/Understanding (16)
• Functional Behaviors (10)
• Critical Behaviors (11)
• Communication Behaviors (7).

The provider instrument included 39 items on a 5-point Likert scale (ranging from Agree Strongly to Disagree Strongly), plus nine true/false (Agree/Disagree/Not Sure) Factual Knowledge items, and a nine-item Communication Literacy Behavior items scale (e.g., “How often do you use plain language, free of jargon?”). The provider instrument included similar domains:

• Belief in Capabilities (8 questions)
• Belief in Rights (9)
• Belief in Value (2)
• Knowledge/Understanding (4)
• Functional Behaviors (5)
• Critical Behaviors (6)
• Communication Behaviors (5).

As part of this research effort, a study was conducted that linked caregiver and provider literacy based on a theoretical model developed by Smith (2005). This model was based on previous research regarding the relationship between general health literacy and health service utilization (Baker et al., 1997; Gordon et al., 2002), and between patient knowledge and service utilization (Kenkel, 1990; Hsieh & Lin, 1997; Parente, Salkever, & DaVanzo, 2005; Smith, 2005). The findings of this research, which used a proxy measure (educational attainment) for mental health literacy, suggested a positive relationship at relatively low levels of mental health literacy (i.e., patient and provider knowledge serving as complements), but a negative relationship at relatively high levels of mental health literacy (i.e., patient and provider knowledge serving as substitutes) (Smith, Armstrong, & Davis, 2006).

Subsequent to this research, Epps, Armstrong, Davis, Massey, McNeish, & Smith (2007), used these instruments in research that created a mental health literacy score for a sample of caregivers who completed the initial caregiver instrument. This score was used in an econometric model against a set of covariates that have previously been shown in the literature (Kenkel, 1990; Hsieh & Lin, 1997) to be determinants of consumer health knowledge. The specific covariates in the model included education, age, gender, race, marital status, employment status, and health status. A second product of this effort was the revision of the literacy instrument. A preliminary analysis of the instrument was conducted to refine and shorten the measure and assess the reliability of the domains. This research resulted in a revised caregiver instrument of 28 items that includes six sub-domains:
• Belief in Values/Capabilities (5 questions)
• Belief in Rights (4)
• Knowledge/Understanding (5)
• Functional Behaviors (5)
• Critical Behaviors (5)
• Communication Behaviors (4).

Study Aims

The current research effort builds on this previous research. The specific aims of the study were as follows:

• To further validate the Mental Health Literacy Questionnaire (MHLQ) with an enhanced sample size.
• To further investigate the relationship between the mental health literacy of providers and caregivers.
• To begin to understand how different message-interventions might raise literacy among providers and caregivers and to investigate the effectiveness of different forms of communication used to disseminate mental health information, including choice counseling.

AIM 1: Further validation of the Mental Health Literacy Questionnaire (MHLQ).

Methods

Sampling

Participants were recruited from caregivers of children receiving mental health services and their service providers in Hillsborough County, Florida. This community serves youth age 0–21 who have been diagnosed with SED, either by the school system according to their behavioral criteria, or by a psychologist according to a DSM-IV diagnosis. Voluntary participants were recruited through the assistance of local service providers, under IRB guidelines as mandated for human participants involved in research studies. Caregivers were paid $25 to participate in the survey. Provider participants were not paid. Completed surveys were obtained from 76 caregivers of children with SED and added to the previous 105 responses received in the 2007 study. Participants who indicated that they had taken the survey previously were eliminated to maintain respondent independence, yielding a final sample of 175. The provider version of the MHLQ was obtained from 29 providers offering services to caregivers completing the MHLQ.
**Analysis**

A total Mental Health Literacy score was created by computing a mean of all the individual item scores. A mean score was selected rather than a sum for our summary statistics to deal with missing data. A scale score for each of the domains was calculated as the mean of all items comprising the scale. The validity and reliability of the MHLQ and subdomains was assessed as follows:

1) Internal consistency as measured using Cronbach’s alpha was assessed to ensure that the overall MHL score and each subscale were reliable and that the items comprising each scale measure the same concept.

2) Construct validity, as calculated by Spearman’s Rho correlations, was assessed through the contrasted groups approach. The overall MHL score and the subscale scores were compared with two variables hypothesized to be related to literacy, experience with mental health services and education. It was hypothesized that greater experience with mental health services and higher education would be positively correlated with mental health literacy.

3) Divergent validity as calculated by Spearman’s Rho correlations was assessed by comparing mental health literacy with variables, such as gender and marital status, that were not expected to be related to literacy.

4) The underlying structure of the sub-domains was assessed and refined through the use of principal components factor analysis. This technique also served to assist in reduction of the number of variables on scales and subscales.

**Results/Discussion**

*Internal consistency.* We hypothesized that the proposed instrument would have internal consistency (e.g., the items in the scale will consistently measure the same concept). Internal consistency was satisfactory for the total MHL scale and all subscales. Cronbach’s alpha for the total MHL caregiver scale (all 28 items) was .921; Belief in Value and Capabilities, .659; Belief in Rights, .783; Knowledge/Understanding, .854; Functional Behaviors, .862; Critical Behaviors, .847; and Communication Behaviors, .853. Cronbach’s alpha for the Factual Knowledge scale, a scale separate from the Health Literacy scale, was .563. The Factual Knowledge scale also had low reliability in the 2007 study, indicating inconsistency in factual knowledge about mental health issues such that knowledge about one mental health issue has a limited relationship to whether or not a person also has knowledge about another mental health issue.

The Cronbach’s alpha reliability estimate for the total 39-item MHL provider instrument was .908; Belief in Values and Capabilities, .606; Belief in Rights, .795 Functional Behavior, .857; Critical Behavior, .852; Communication Behavior, .611, and, Communication Assistance, .647. Cronbach’s Alpha for the Factual Knowledge scale was .525. Cronbach’s alpha scores above .8 are generally considered strong.
Construct validity. We hypothesized that the proposed instrument would have construct validity, with mental health literacy positively correlated to experience with mental health services and to the education level of caregivers. According to a Spearman’s Rho, there was a small, but statistically significant correlation (p=.015) between the mental health literacy score and the number of years participants’ families have been receiving services. There was also a statistically significant negative relationship between the length of receipt of mental health services and the Belief in Value and Capabilities (p=.000) and Critical Behavior (p=.04) sub-scales, indicating that the longer a caregiver had been receiving services, the lower his/her scores on these two subscales.

There was a statistically significant relationship between the length of receipt of mental health services and “Factual Knowledge” (p=.013). While there was not a statistically significant relationship between the overall score and caregiver education, there was a negative statistically significant relationship between the education of the caregiver and the Belief in Value and Capabilities sub-scale (p=.03). There was a statistically significant relationship between the caregiver’s education and Factual Knowledge (p=.000).

Divergent validity. We hypothesized that mental health literacy would not be related to unassociated factors such as gender or marital status. According to a Chi Square, at a 95% confidence level, there is a statistically significant association between marital status and overall MHLS (p=.05) such that those who are divorced tend to have low literacy, while those who are married have moderate literacy, and those who are separated have higher literacy scores. There was not a statistically significant association between gender and overall MHLS, but according to a t-test of means, there was a statistically significant difference between males and females’ scores on the “Critical Behaviors” (p=.03), and “Communication Behaviors” (p=.02) subscales.

Refinement of Sub-Domains. As an exploratory study and to test the potential of reducing and simplifying the MHL, a principal component factor analysis of the 29-item MHLSQ was conducted. The factor analysis identified a potential three-factor solution that accounted for 54% of the variance. The three factors identified included Knowledge and Competency, Belief in Family Agency, and Belief in Control.

The first factor included 18 items from four sub-scales. A revised scale was drafted utilizing those items that contributed most to the overall internal consistency of each sub-domain scale by looking at the effect omitting each item would have on the overall alpha reliability estimate. The factor loading of the items on the principal components factor analysis was then reviewed for appropriateness of selection. Factor loadings for all items exceeded .618. The resulting scale included six items from the original four domains. The suggested revised Knowledge and Competency sub-scale would consist of the following items:
• I know what some of the risks are to the treatments recommended by our providers.
• I know how to find treatment options for my child/family when necessary.
• I understand how to obtain the services/resources we need.
• I understand how to obtain the information we need for our care/well-being.
• I am able to decide when I need to switch providers or see an additional provider.
• I am capable of negotiating with our service providers to reach treatment or service solutions that are best for everyone.

The second factor included six items from two original sub-scales. Factor loadings for all items exceeded .442. The suggested revised sub-scale Family Agency was related to the caregiver’s ability to be in control of the destiny of his/her family and/or child and would consist of the following items:

• I am capable of being a good parent to all my children.
• The mental/emotional/behavioral problems in my child can be successfully treated.
• My child and family have the right to receive testing we need.
• I have the right to ask for help when I need it.
• I have the right to ask for all available services in the community that my child or family needs.
• I have the right to choose my child’s services.

The third factor included statements referring to the caregiver being in control of his/her family, child, and treatment. Factor loadings for all items exceeded .496. The suggested revised sub-scale, Belief in Control, consisted of three statements from the original sub-domain, Belief in Values/Capabilities, and included the following items:

• I am capable of solving my or my family’s problems.
• I can control my child’s behavior.
• Treatment for my family is under my control.

Internal consistency. Cronbach’s alpha for the three new subscales were Knowledge and Competence, .883; Family Agency, .726; and Belief in Control, .635. The Cronbach’s alpha on the 15-item version Mental Health Literacy scale was .804.

Construct validity. The revised sub-scales exhibit construct validity related to the experience with mental health services, and to the education level of caregivers. There was a statistically significant correlation between the number of years participants’ families have been receiving services and the Family Agency sub-scale (p=.015), and the Belief in Control sub-scale (p<.001). There is also a statistically significant correlation between the Belief in Control sub-scale and the caregiver’s education level (p=.008). Factual Knowledge was also significantly correlated with the revised Knowledge and Competency sub-scale (p=.005).
Divergent validity. There were not statistically significant differences for gender or marital status on any of the revised sub-scales.

Conclusions

Analysis of the caregiver MHLQ supports the internal reliability and preliminary validity of the instrument as a measure of mental health literacy. Further analysis suggests that the five subscales identified in the 29-item survey may be reducible to a shorter, potentially more convenient 15-item survey that still maintains similar psychometric properties. The three-factor model encompasses the dimensions of Knowledge and Competency, Family Agency, and Belief in Control.

AIM 2: Investigation of the relationship between the mental health literacy of providers and caregivers through semantic networks.

Methods

To address this aim, semantic networks among caregivers and providers were compared. A semantic network has been defined as a conceptual cluster of similar beliefs and understandings (Monge & Eisenberg, 1987). In this study, we extrapolated the knowledge and beliefs scores from the MHLQ of the providers and their corresponding caregivers. We compared means of providers on the literacy statements and dimensions with those of the caregivers to study semantic networks (Monge & Eisenberg, 1987) to see how the messages (beliefs and understanding) held by providers relate to caregiver literacy.

Results/Discussion

Mean scores for providers on each of the subscales were computed as a simple mean of all items. Providers scored highest on the Belief in Rights domain, followed by the Belief in Values and Capabilities, Communication, Critical Behaviors and Functional Behaviors. The Factual Knowledge domain was the lowest scoring subscale.

Under the Belief in Rights domain, providers most agree with items such as families and children having the right to be treated with respect, receive an education, ask for help, ask questions, and choose services. They are less likely to agree with items such as families and children having the right to be heard by the provider or receive any or all services or testing they request or need.
Under the Belief in Values and Capabilities domain, providers most agree that having mental, emotional, or behavioral problems does not make a child less valuable to society, that a family’s opinions are important, that families are worth helping, that mental illness is treatable, that people can lead a normal life despite having a mental illness, and that families have many strengths. They are less likely to agree that families are capable of complying with treatment or advice, that families genuinely want help, and that families are open with providers.

Under the Communication domain, providers feel most confident in their ability to convey understandable information to families, in ways that are culturally competent, and in ways that facilitate open information exchange. They feel less confident in reading clients’ non-verbal reactions and taking in information from clients so that they can accurately diagnose.

Under the Critical Behaviors domain, providers are most comfortable in making referral-related and safety decisions and less comfortable making treatment or diagnosis-type decisions. Mean scores for each variable in each domain for providers are provided in Appendix A.

Mean scores for each variable in each domain for caregivers are provided in Tables 1-4. Caregivers most highly rated the Family Agency sub-domain, giving high scores for being a good parent; believing that their child’s problems can be treated; and believing that their family has a right to testing, help, services, and choice. Interestingly, these are the types of statements also most highly rated by the providers.

<table>
<thead>
<tr>
<th>Table 1. Mean Scores for Caregivers, Family Agency Domain</th>
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<tr>
<td>N</td>
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<tr>
<td>-------------</td>
</tr>
<tr>
<td>Family Agency</td>
</tr>
<tr>
<td>I am capable of being a good parent to all my children.</td>
</tr>
<tr>
<td>The mental, emotional, and/or behavioral problems in my child can be successfully treated.</td>
</tr>
<tr>
<td>My child and family have the right to receive testing we need.</td>
</tr>
<tr>
<td>I have the right to ask for help when I need it.</td>
</tr>
<tr>
<td>I have the right to ask for all available services in the community that my child or family needs.</td>
</tr>
<tr>
<td>I have the right to choose my child’s services.</td>
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Caregivers rated the “Knowledge and Capability” sub-domain moderately high, giving highest scores on communication and critical decision-making behaviors. Providers also rated their own skills on these behaviors moderately, relative to their scores on the other domains.
Table 2. Mean Scores for Caregivers, Knowledge and Capability Domain

<table>
<thead>
<tr>
<th>Knowledge and Capability</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
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<tbody>
<tr>
<td>I understand any changes my providers want us to make.</td>
<td>169</td>
<td>4.07</td>
<td>1.024</td>
</tr>
<tr>
<td>I know what mental health resources and services are available to us.</td>
<td>170</td>
<td>3.85</td>
<td>1.099</td>
</tr>
<tr>
<td>I know how to access all the resources, services, and treatments available in this community.</td>
<td>171</td>
<td>3.42</td>
<td>1.226</td>
</tr>
<tr>
<td>I know what some of the risks are to the treatments recommended by our providers.</td>
<td>171</td>
<td>3.84</td>
<td>1.115</td>
</tr>
<tr>
<td>I know what some of the benefits are to the treatments recommended by our providers.</td>
<td>171</td>
<td>4.12</td>
<td>1.115</td>
</tr>
<tr>
<td>I know how to find treatment options for my child/family when necessary.</td>
<td>171</td>
<td>3.78</td>
<td>1.125</td>
</tr>
<tr>
<td>I understand how to obtain the services/resources we need.</td>
<td>172</td>
<td>3.91</td>
<td>1.083</td>
</tr>
<tr>
<td>I understand how to obtain the information we need for our care/well-being.</td>
<td>171</td>
<td>4.05</td>
<td>1.005</td>
</tr>
<tr>
<td>I understand how to juggle my child's appointments and activities.</td>
<td>167</td>
<td>4.27</td>
<td>1.060</td>
</tr>
<tr>
<td>I understand how to fit our treatments into our life.</td>
<td>169</td>
<td>4.28</td>
<td>1.051</td>
</tr>
<tr>
<td>I am able to decide when I need to get a second opinion on our care.</td>
<td>170</td>
<td>4.49</td>
<td>1.083</td>
</tr>
<tr>
<td>I am able to decide when I need to switch providers or see an additional provider.</td>
<td>171</td>
<td>4.44</td>
<td>0.901</td>
</tr>
<tr>
<td>I am able to decide whether or not the treatments/services provided have worked well enough or not.</td>
<td>171</td>
<td>4.49</td>
<td>0.901</td>
</tr>
<tr>
<td>I am able to decide when my family needs help, assistance, or services.</td>
<td>171</td>
<td>4.62</td>
<td>0.615</td>
</tr>
<tr>
<td>I know when my child/family needs to make changes in our lives.</td>
<td>170</td>
<td>4.54</td>
<td>0.663</td>
</tr>
<tr>
<td>I am capable of asking questions of our service providers.</td>
<td>171</td>
<td>4.67</td>
<td>0.693</td>
</tr>
<tr>
<td>I am capable of expressing concerns to our service providers.</td>
<td>170</td>
<td>4.69</td>
<td>0.856</td>
</tr>
<tr>
<td>I am capable of negotiating with our service providers to reach treatment or service solutions that are best for everyone.</td>
<td>170</td>
<td>4.34</td>
<td>0.856</td>
</tr>
<tr>
<td>I am capable of asking for help, services, treatment, and resources in a way that gets us what we need.</td>
<td>170</td>
<td>4.39</td>
<td>0.886</td>
</tr>
</tbody>
</table>

Caregivers rated the Belief in Control sub-domain the lowest of the three sub-domains, indicating lower confidence in their ability to control or solve their family’s problems or issues. Providers rated their own functional behaviors the lowest of all of the sub-domains.

Table 3. Mean Scores for Caregivers, Belief in Control Domain

<table>
<thead>
<tr>
<th>Belief in Control</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>I can control my child’s behavior.</td>
<td>174</td>
<td>3.24</td>
<td>1.181</td>
</tr>
<tr>
<td>Treatment for my family is under my control.</td>
<td>173</td>
<td>3.74</td>
<td>1.060</td>
</tr>
<tr>
<td>I am capable of solving my or my family’s problems.</td>
<td>175</td>
<td>3.80</td>
<td>0.928</td>
</tr>
</tbody>
</table>
Conclusions

Results indicate that providers and caregivers rated items similarly. Both groups rated a belief in the family’s agency (the right and ability to control their own destiny) the highest of all sub-domains; and both rated their own communication behaviors and knowledge moderately among all sub-domains. Caregivers rated their perceived control over their family or child relatively low, while providers rated their own functional behaviors relatively low.

AIM 3: Multivariate Analysis of the Relationship Between Provider and Caregiver Mental Health Literacy.

Methods

In previous research (Epps et al., 2007), a mental health literacy score was created for each of the caregivers who completed the caregiver instrument, and regressed in an econometric model against a set of covariates that have previously been shown in the literature (Kenkel 1990, Hsieh and Lin 1997) to be determinants of consumer health knowledge. The specific covariates in our model included, education, age, gender, race/ethnicity, marital status, and health status.

In this year’s study, because we coordinated the administering of the caregiver and provider instruments, we have responses from caregivers and their corresponding providers. The econometric model includes comparing the relationship between the average mental health literacy of the provider organization (using the mean value of the mental health literacy score for all providers in the same organization) and the caregiver’s mental health literacy. The original sample for this econometric model consists of the 76 caregiver respondents to the 2008 community survey. However, the sample excludes caregivers for whom a provider could not be identified. The final sample therefore consists of 50 caregiver observations. As this sample size is small, results must be conservatively interpreted.

Because the distribution of the caregiver mental health literacy scores reflect a normal distribution, we specifically estimated a “probit” econometric model, with the dependent variable constructed as a binary variable, equal to 0 if the value of the caregiver mental health literacy score was equal to or below the sample median, and equal to 1 if above. Thus, the model estimates the probability a caregiver has above-median mental health literacy.

In addition to the key independent variable, the average provider mental health literacy of the organization, the model includes the previously listed demographic and socioeconomic variables (education, age, gender, race/ethnicity, marital, and health status), as well as other variables that reflect factors that were hypothesized to independently influence caregiver mental health literacy. These include whether the caregiver is currently, or has ever been, covered by public insurance (Medicaid) for physical or mental health services, and a measure of the length of time (either less than one year, or one year or more) the caregiver has been utilizing mental health services for the child.
Results/Discussion

Table 4 below provides descriptive statistics of all variables used in the model. It should be noted that the mean mental health literacy score at the organization level is much less than that at the individual-provider level, which reveals that much of the variation in provider literacy occurs within an organization. However, because of the reduced variation in this measure in its original, continuous form, it would likely have minimal impact in the econometric model. Thus, for provider-organization mental health literacy, we created three dichotomous (“dummy”) variables, which indicate the rank of the organization (low, middle, or high) in terms of overall mental health literacy.

<table>
<thead>
<tr>
<th>Variables:</th>
<th>N</th>
<th>Mean/Median</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Caregiver MH Literacy</td>
<td>50</td>
<td>12.04/12.17</td>
<td>1.3121</td>
</tr>
<tr>
<td>Overall Provider-Organization MH Literacy</td>
<td>3</td>
<td>4.51</td>
<td>0.0606</td>
</tr>
<tr>
<td>Less than High School</td>
<td>50</td>
<td>0.20</td>
<td>0.4041</td>
</tr>
<tr>
<td>High School</td>
<td>50</td>
<td>0.42</td>
<td>0.4986</td>
</tr>
<tr>
<td>College</td>
<td>50</td>
<td>0.38</td>
<td>0.4903</td>
</tr>
<tr>
<td>Age</td>
<td>50</td>
<td>41.82</td>
<td>11.4815</td>
</tr>
<tr>
<td>Female</td>
<td>50</td>
<td>0.84</td>
<td>0.3703</td>
</tr>
<tr>
<td>Black</td>
<td>50</td>
<td>0.22</td>
<td>0.4185</td>
</tr>
<tr>
<td>Other Race</td>
<td>50</td>
<td>0.12</td>
<td>0.3283</td>
</tr>
<tr>
<td>White</td>
<td>50</td>
<td>0.64</td>
<td>0.4849</td>
</tr>
<tr>
<td>Hispanic</td>
<td>50</td>
<td>0.22</td>
<td>0.4185</td>
</tr>
<tr>
<td>Married</td>
<td>50</td>
<td>0.40</td>
<td>0.4949</td>
</tr>
<tr>
<td>Health Status: Very Good/Excellent</td>
<td>50</td>
<td>0.36</td>
<td>0.4849</td>
</tr>
<tr>
<td>Covered by Medicaid</td>
<td>50</td>
<td>0.36</td>
<td>0.4849</td>
</tr>
<tr>
<td>Years Receiving Service: ≥1 year</td>
<td>50</td>
<td>0.70</td>
<td>0.4629</td>
</tr>
</tbody>
</table>

The results of the probit model are presented in Appendix B, based on the revised, 15-item instrument and the three sub-domains of caregiver mental health literacy (Knowledge and Competency, Belief in Family Agency, and Belief in Control) as the dependent variables. In each case, the dependent variable is dichotomous, indicating below (a value of 0), or at or above (a value of +1) the sample median, with the model estimating the probability the dependent variable is above the sample median. Because the probit is a non-linear model, the usual estimated coefficients (the “betas”) do not directly reflect the impact of the independent on the dependent variable. Therefore, the results presented are translated from the estimated coefficients, showing the actual marginal effect of each covariate on the probability a caregiver achieves an above-median literacy score. Inferences are made at the .05 (***) and .10 (*) level of statistical significance.
Because this model uses cross-sectional data, the possibility arises that there are unaccounted for factors, or excluded variables from the model, that would lead to bias in the observed estimated effects of the included variables on the independent variable, particularly if any excluded factor would be systematically related to any of the independent variables. For instance, studies consistently show that children with diagnosed mental illness also have lower educational achievement than other children (Farmer 1993, 1995; Mannuzza and Klein 2000; Currie and Stabile 2006). Thus, given the setting of this study, if the caregiver ever experienced (or has) a mental health condition, that condition would not only potentially be an influence on the caregiver’s level of mental health literacy, but also the caregiver’s educational achievement. In this case, an important omitted factor would be the caregiver’s mental health condition. Therefore, we included one additional variable to the right-hand side of the model, a dummy variable indicating whether the caregiver has ever received mental health services for their own condition. Among the 50 caregivers in our sample, 62 percent of (or 31) respondents indicated they have at one time received mental health services for their own conditions.

As seen in the probit model results (Appendix B), with overall mental health literacy as the dependent variable, only gender and marital status were significant. Results indicate that a female is 40 percentage points more likely than a male to have a high level of mental health literacy (p<.05), while a married individual (meaning either formally married, or living as married) is almost 30 percentage points more likely (p<.10) to have a high level of mental health literacy than someone who is unmarried.

In the remainder of the table, the effects of the covariates on each of the sub-domains of caregiver mental health literacy are examined. For the first domain, Knowledge and Competency, the literacy level of the provider is significant in determining the mental health literacy of the caregiver. Results suggest that caregivers receiving services in the highest ranked provider organization are 100 percent more likely to have high Knowledge and Competency scores than caregivers in the lowest ranked provider organization. In addition, caregivers with some level of education at the collegiate level are moderately more likely (p<.10) to have high knowledge and competency literacy than those with lower levels of educational achievement. These results are what we might expect for this domain of caregiver literacy.

For the results related to the second sub-domain, Belief in Family Agency, there are more covariates with statistical significance, although some of the results were unexpected. For instance, an individual who is (or has been) covered by Medicaid is more likely than someone who has not been covered by Medicaid to have a high score on this dimension of mental health literacy. An inverse relationship was found between years of receiving service and the probability of having a high level of Belief in Family Agency, suggesting that the longer a caregiver had been receiving service for their child, the less likely they were to endorse items such as “The mental, emotional, and behavioral problems in my child can be successfully treated,” and “I have the right to ask for help when I need it.”

The results for the last domain, Belief in Control, suggest that caregivers who receive services from provider organizations with relatively high levels of mental health literacy are less likely to have a high level of Belief in Control. They are less likely to endorse items such as “I can control my child’s behavior,” and Treatment
for my family is under my control.” In addition, non-white (not Hispanic) caregivers are more likely to have high levels of Belief in Control than are white caregivers. Further, caregivers who have ever received services for their own mental health conditions are less likely to have a high level of Belief in Control. For this last result, it is plausible that while caregivers who have had more mental health services might be more literate, the fact that they may be suffering from their own mental health condition could diminish their sense of, or belief in, being in control of their families’ circumstances.

**Conclusions**

The small sample sizes available in the current study indicate that the results must be interpreted cautiously. With this limitation, the results raise interesting questions about the relationship between caregiver and provider literacy. The results associated with Knowledge and Competency are consistent with previous research and suggest a positive relationship between provider and caregiver mental health literacy. Results for Family Agency and Belief in Control sub-domains suggest that mental health literacy is a complex concept, and that sub-domains may not be univariately related, with Belief in Control negatively related to provider literacy. More research with larger sample sizes is needed to address these findings.

**AIM 4: Investigation of the effect of different message-interventions to raise literacy among providers and caregivers and to assess the effectiveness of different forms of communication.**

**Methods**

To investigate message interventions to raise literacy, focus groups were conducted to investigate the ability of different message-interventions (training programs, brochures, DVDs, etc.) to raise literacy among providers and caregivers and discuss with caregivers and providers the effectiveness of different forms of communication. Four information sources were utilized in the focus groups.

First, group participants were asked to discuss issues associated with sources of information they utilized to learn about 1) mental health issues and when and how providers’ information-sharing is helpful/preferred, 2) the priority of topics, concepts, ideas, and thoughts a person would need to know and understand in order to be able to fully communicate with their health care provider.

Second, focus group participants were asked to create and discuss a collage of photographs and pictures representing “what it is like being a member of a family with a child with a disability,” from images they cut out of randomly selected magazines. The purpose of this exercise was to understand how participants construct these experiences through language and images, to obtain ideas to use for language and imagery in future message design, and to see if providers and caregivers use similar language and imagery in their discussions.
Third, focus group participants were given a list of possible topics to be covered in a message intervention. These topics were derived in previous focus groups, and included 68 generated items that were related to caregiver and provider mental health literacy. Participants performed a card sort and rank order of the items in terms of importance to a message intervention for caregivers to improve their mental health literacy, and a message intervention for providers to help them help caregivers.

Finally, participants were asked to sort cards listing communication channels (i.e. DVD, brochures, workshops) that might be used to convey mental health information. Participants were encouraged to share their observations and “think out loud” during group activities.

The focus groups were audiotaped and transcribed. Focus groups were analyzed by both content analysis and by using a constructivist-grounded theory analytical approach (Charmaz, 2000; Glaser & Strauss, 1967; Strauss & Corbin, 1990), in which a line-by-line, systematic coding of data yielded findings based on observed patterns and themes. The line-by-line codes were translated into broad themes, which were then collapsed into metacodes—themes and concepts that best address the research questions. In this report, observed categories are substantiated by illustrative comments.

**Sampling**

Three focus groups were conducted with caregivers and two focus groups were conducted with providers of mental health care services for children with SED and their families. Some of the caregivers also work as providers. Provider participants were case managers and family advocates from area children’s mental health agencies. Our research site for these focus groups was in Hillsborough County, Florida. This community serves youth ages 0–21 who have been diagnosed with SED, either by the school system according to their behavioral criteria, or by a psychologist according to a DSM-IV diagnosis. Voluntary participants were recruited through the assistance of local providers. Caregiver participants were paid $25. Provider participants were not paid.

**Results/Discussion**

Results of the focus group analysis are grouped by 1) Sources of Information, 2) Topics for Message Interventions, 3) Language and Imaginary expressed in focus group activities, and 4) Channels of Information. Data from each set of activities is included where relevant.

**Sources of Information**

Information sources can be good or poor, depending on how accurate and helpful they are. Very little information is consciously obtained about mental illness from the mass media. Caregivers didn’t think much about mental health or mental illness until their child had problems, and they obtained information on an ‘as needed’ basis, when their child exhibited problems and to the extent that they obtained information on an ‘as needed’ basis, when their child exhibited problems and to the extent that they interpersonal inquiries directed at formal systems such as police or mental health and the school system. Representative comments included:
“I never really knew anything about mental health or nothing like that and I really never even cared for it until I had to receive it.” (CAREGIVER)

“Growing up, I knew nothing about mental illness.” (CAREGIVER)

“I can remember when my daughter was first diagnosed, they gave me the results from the test and just sent me on my merry way.” (CAREGIVER)

“I had to advocate for services for her and ask questions like, will she get better, will we be doing this all of our life, is there better treatment for her, where can I access, and I got no answers so it was kind of frustrating. She was put into a day treatment center and there she got the help that she needed. . . . I started meeting people . . . within the school system that was able to help me get my kids the services and things that they needed.” (CAREGIVER)

“I had to make phone calls, the teachers at my daughter’s school, they were not helpful.” (CAREGIVER)

Information about mental illness and mental health also came from families and cultural sources:

“A lot of it I think comes from their families of origin and they just kind of—even when educationally they have learned better, when they are stressed, that is what they fall back on.” (PROVIDER)

“I probably expand that to culture and those kinds of things, notions that are sometimes multi-generational, internet, word of mouth, a lot of TV.” (PROVIDER)

Other current helpful sources of information include sources such as the internet in general and disorder-specific websites, in addition to more informal interpersonal sources such as support groups and resource centers.

“Federation of Families for Children’s Mental Health, I have gone to the NAMI website, I have gone to several different ones. . . lots of sites.” (CAREGIVER)

“I am signed up for the bipolar manic depression website, so every time there is new information, they automatically send me the updates.” (CAREGIVER)

“Resource Centers because they have a lot of the information.” (CAREGIVER)

“I think it is really good for parents to belong to support groups because that way, you really realize that you are not the only one feeling like you are.” (CAREGIVER)

“Sometimes they will come in and say I was looking at stuff on the Internet and at least you think they may have looked up WebMD or they might have gotten abold of a parent chat room where they might have gotten some real information, at least have a grip on what the issues might be and I even sometimes cringe when they say pediatrician. Board Certified Child Psychiatrist I sometimes feel a little better about, but many of the pediatricians I find, even the specialty doctors don’t get it.” (PROVIDER)

“I send them to the Web to read some of that stuff because then they tend to find other stuff they might read, a chat room for parents, or refer them to other parents that are sort of leaders in that area where they can get a parent perspective.” (PROVIDER)
Background, cultural, contextual, and subconscious information about mental illness is obtained from multiple sources, and some caregivers could not name particular media sources of information. To these caregivers, they rely on their own insights to the best of their ability:

“Instinct maybe, like working with my son because I knew he wasn’t dumb. . . . I just knew there had to be a reason [for his behavior] . . . So is that intuition or gut feeling.”
(CAREGIVER)

“Back then it was kind of hard because I didn’t know anything about the mental health field, I didn’t know who to turn to, that is why I was doing it all myself and it is very, very frustrating with no support, nobody to help you out.” (CAREGIVER)

“With me, it was the Baker Acting of my son. . . . I had to have the Sheriff’s Department come out three times and the third time is when they finally found out what he had. . . . “Because he tried to kill his sister. . . . Get on the phone with 9-1-1 and it scared me. . . .” (CAREGIVER)

**Information/messages from providers**

Providers give families information from a unique point of view. They can tell caregivers what the child is saying to them, and they can provide caregivers with a great deal of practical information, often in written (brochure) format. Helpful providers give information on resources and system navigation and speak the parents’ language. They also give the families hope:

“A lot of times the kids don’t want to tell the parents they are fearful, where they will talk to the doctor or someone if it makes them more comfortable.” (CAREGIVER)

“I think the agencies need to help teach the parents. Parents are coming in with problems with their children don’t understand and a lot of these parents don’t understand the language they are using up here, the agencies actually have to come down to their level and they won’t do that, so the parents and the child suffers.” (CAREGIVER)

“I really try to talk on a level that they are going to understand. . . . I think on a 6th grade level or below, or if there is a child that has some developmental issues to really try to use their language and not use acronyms and big words that are scary and to paraphrase their own language as much as possible.” (PROVIDER)

“They keep the parent informed of what is happening and what is available, that can draw the parent’s strength, if they are going to keep negatively [sic] the parent, the parent is going to give up eventually and the child is going to suffer. I think the agency has got to give them strength and keep them positive to help the child.” (CAREGIVER)

Providers also enhance the well-being of the child and family by listening to them, helping them acknowledge and identify their own resources and strengths, and help them develop concrete plans and actions:
“I help them to recognize that they are unique and that there is not always a right or wrong, it is just who they are and what is specific to them and that they are part of the solution, that’s the biggest part really, and that they have the resources within themselves, they just need some coaching.” (PROVIDER)

“To help them use their own language, develop their own language about their family strengths and needs and culture.” (PROVIDER)

“I think also it is not just a matter of talking in very abstract interventions, I think helping them come to some planning about what they can do and take some action is usually very helpful because sometimes they have just been so overwhelmed and floundering that it is very grounding for them.” (PROVIDER)

“Sometimes people with disabilities have had so many decisions made for them they don’t even know how, they don’t expect to and so just really refusing to do that [for them] and give them whatever time and encouragement they need to make their own decisions, sometimes just waiting silently while they make up their mind about something because . . . see these kids that are going into adulthood and never made a decision in their lives.” (PROVIDER)

**Topics/concepts for message Interventions**

Throughout the focus group discussion, caregivers mentioned many concerns or issues that should be addressed in any training or messages to help them better cope with and be in control of their children’s problems. Providers also mentioned issues that they believed were salient to the delivery of messages to caregivers. A problem-solution message would include solutions to, or advice about, the following problems and issues:

1) Caregivers suffer from a lack of information about their child’s disorder, and often don’t know where to turn to get information. (CAREGIVERS)

2) Caregivers receive results from testing without an explanation as to what they mean or guidance as to the next steps. (CAREGIVERS)

3) Caregivers don’t know how to talk to their children’s teachers in a way that is helpful. (CAREGIVERS)

4) Caregivers don’t know how to facilitate and expedite school-based testing or evaluation for their children. They don’t know how to request school placement for their children. (CAREGIVERS)

5) Caregivers don’t know what services are available or how to access these services. There are insufficient services available. (CAREGIVERS AND PROVIDERS)

6) Caregivers don’t know where to turn for help. (CAREGIVERS)

7) Children don’t understand their illness or diagnosis, and they feel different or abnormal. (CAREGIVERS)

8) Caregivers don’t know how to include their children in their treatment or treatment planning. (CAREGIVERS)

9) Caregivers don’t know what to do to control their child’s behavior. (CAREGIVERS)

10) Siblings, spouses, and other family members get short-changed. (CAREGIVERS)

11) Caregivers are concerned about the financial futures for their families. (PROVIDERS)
12) Families are not educated about mental health issues. (PROVIDERS)
13) Caregivers struggle with getting all of their doctors on the same page. (PROVIDERS)
14) Medications have unwanted side effects. (PROVIDERS)
15) Services can be a closed door without adequate insurance; payment options are inadequate. Insurance limits choices. (PROVIDERS)
16) The healthcare system is hard to navigate and access without someone fighting for you. (PROVIDERS)
17) Transportation to services is a challenge. (PROVIDERS)
18) Poverty is a challenge. (PROVIDERS)
19) Families need more of a support system. (PROVIDERS)
20) The quantity of paperwork takes away from the quality of services. (PROVIDERS)
21) Families need to be taught how to be self-sufficient. (PROVIDERS)

Messages could also resonate with caregivers if they acknowledge and address the feelings and emotions experienced by caregivers:

1) Children’s disorders and disabilities are emotional/stressful issues for their caregivers. (CAREGIVERS)
2) Caregivers feel that they are to blame for their children’s problems. (CAREGIVERS)
3) Caregivers deal with their children’s/family’s problems in self-destructive ways (excessive eating, drinking; not sleeping). (CAREGIVERS AND PROVIDERS)
4) Caregivers fear losing their children. (CAREGIVERS)
5) Caregivers feel frustrated, discouraged, unsupported, terrified, guilty (at blame), weak, confused. (CAREGIVERS AND PROVIDERS)
6) Siblings are traumatized by children’s disorder/behavior. (CAREGIVERS)
7) Caregivers feel a lack of control. (CAREGIVERS)
8) Having a child with a disability or disorder is unfair. (CAREGIVERS)
9) Caregivers feel unwelcome by providers. (CAREGIVERS)
10) Caregivers need to succeed—they need to prove they can succeed. (CAREGIVERS AND PROVIDERS)
11) Helping their children takes a lot of work and effort. It is intense, complicated, and busy. (CAREGIVERS AND PROVIDERS)
12) Caregivers are continually dealing with change. Families’ problems are continual, 24/7, constant. (CAREGIVERS AND PROVIDERS)
13) Caregivers do not feel understood by providers or the system. (CAREGIVERS)
14) Caregivers feel lonely, isolated, and secluded. They think that nobody cares. (PROVIDERS)
15) Families need to reach out to each other and spend more time together. (PROVIDERS)
16) Caregivers are concerned about the price of care. (PROVIDERS)
17) Families are frustrated because reality is often not what they would want. (PROVIDERS)
18) Society forgets about people with needs and disabilities; these are forgotten kids. (PROVIDERS)
19) Families need hope. They need to believe that things will get better. They need validation. (PROVIDERS) (“Your just have to know that there is hope
for you that tomorrow will come;” “There are people there to help. You are not the first ones that have been through this, give them some sense of hope of future what might it look like, we could put some supports in place or can you imagine yourself in this way because sometimes people don’t seek help until they are absolutely crumbling.” (PROVIDER))
20) Families feel as if they’re always starting over again and again. They feel lost. (PROVIDERS)
21) Caregivers feel disempowered and desperate. (PROVIDERS)
22) Families need to be encouraged. (PROVIDERS)
23) Caregivers need an array of information, like a menu. (CAREGIVERS)
24) Mental illness is “not a warm and fuzzy feeling”. (CAREGIVERS)
25) Services have been “chopped and deleted, like a juggling act.” (CAREGIVERS)

Similar messages were identified in the collages that caregivers constructed:

1) Caregivers feel blamed/at fault/guilty for child’s problems.
2) Caregivers feel alone, by themselves.
3) Caregivers feel stressed/emotional/confused.
4) Caregivers need family, friends, community as source of support and hope.
5) Families need to know there is help available.
6) Children are confused about their disorders and treatments/testing.
7) Children feel different.
8) Children feel lacking.
9) Helping their child/family requires a great deal of effort on the part of the caregiver.
10) Caregivers need to feel supported.
11) Caregivers fear losing their children.

The main messages providers constructed in their collages included:

1) Care is pricey.
2) It takes patience.
3) It is okay to dream.
4) We have to believe we can succeed.
5) There is hope.
6) Families with special needs feel separate from normal families.
7) Community services are links between families with special needs and the community.
8) It is very intense, complicated, and busy for families.
9) There is hope and love.

The results of the card sort of 68 topics related to message intervention. While caregivers wanted to rate all items highly, when they were pressed to rank order the items, the top items to be addressed in a message intervention, according to the caregivers, were:
1) How I can survive the problems my child and family are going through.
2) How I can help things get better for my child and family.
3) The rights I have to be heard by my child’s service providers.
   The belief that my opinions are important (“Don’t just buy whatever is being told. Parents need to learn how to advocate and research things.”) (CAREGIVER)
4) The belief that my opinions of my child are important.
5) How to balance the benefits and side effects of medication and determine whether or not my child should be taking them.
6) How to make placement decisions about my child.
7) How to ask for help, services, treatments, or resources in the way that my child and family get what we need.
8) The belief that mental, emotional, and behavioral problems do not make my child less valuable (“It makes you feel more normal because you are valued because of who you are and you are not put down or feeling useless because you have an illness, that’s important.”) (CAREGIVER)
9) The belief that mental, emotional, and behavioral problems in a child can be mental illness and not discipline issues.
10) How to be a good parent to all my children (“I believe every parent wants to be a good parent… just helping parents to live out their dream because their dream is to have good kids, let the kids be successful.”) (CAREGIVER).

In addition, caregivers state that they need training on: the IEP process, insurance navigation, medication administration, and filling out paperwork. They also need information on their right to be treated with respect; their right to know what services are available; and their right to get their child tested.

According to providers, the top ranked topics for their own training included:

1) How to make a diagnosis/assessment.
2) How to help families figure out how to pay for treatments, services, and medications; (“That is a tough, tough one and we do some of that but there is not a lot of choices when it comes to that in the community;” “Because there is so little, it is good to know more.”).
3) How to figure out if the behavior of a child is the result of mental illness or discipline problems.
4) How to identify alternative treatment options for families.
5) How to develop a therapeutic relationship with the families they work with.
6) How to make placement decisions about a child.
7) How to ask for help/service/treatment/resources in a way that the child/family get what they need.
8) The belief that mental, behavioral, and emotional problems do not make a child less valuable.
9) The belief that mental, behavioral, and emotional problems in a child can be an illness and not a discipline issue.
10) How to help a parent be a good parent to all their children.
11) How to balance the benefits of side effects of medication and determine whether the child should be taking them.
12) How to maintain hope for families/How to maintain hope that the families I work with have many strengths that enhance their health and well-being.
13) How to help form a therapeutic relationship that facilitates communication, disclosure, and information.
14) To know that families have the right to be heard, respected, and make their own choices.
15) How to understand that mental, emotional, and/or behavioral problems do not make a child less valuable.
16) Mental health resources and services that are tailored to fit the needs and strengths of families and improve access. ("We are always on the search.").

The language and imagery used by caregivers and providers

People experience information in the sensory form (sights, sounds, feelings, tastes, smells) in which they were first aware of the information. In conversation, these sensory forms representing how we are experiencing a situation often come out in our speech choices—people often speak in one of three representational systems (O’Connor & Seymour, 1993): Kinesthetic (related to touch, sensory input, or feelings), Auditory (related to hearing or auditory input), or Visual (related to sight or visual input. Other representational systems sometimes heard in discourse include Gustatory (taste-related) or Olfactory (smell-related). Often this language is colorful and metaphorical.

Communicating with people in kinesthetic mode might include hands-on demonstrations or role-playing or specifically addressing their feelings or emotions, and would include the use of kinesthetic language, imagery, and metaphors ("hard work," for example). Communicating with people in auditory mode might include using CDs and perhaps telling stories, and would include the use of auditory language and metaphors ("telling a story," for example). In the following quote, the provider describes using a primarily auditory experience to change a caregiver’s visual and kinesthetic construction of the situation:

“Occasionally I have used my own family, especially with kids and my success, as I like to call it, is with families who have kids like my own age and one particular family I am thinking about is a kid who went to the school that my child is going to and the experiences that both kids had, and I talk about my issues with my child at that age and kind of explain how I dealt with it to make changes and hopefully that would let the family see that they are not alone, that we have something in common that maybe she can use.” (PROVIDER)

Communicating in visual mode might include DVDs or live speakers and written materials, and would include the use of visual language and metaphors ("painting a picture," for example). Mixed channels include message interventions such as support groups or in-person training, which use primarily auditory mode but touch on all three.

Caregivers used a great deal of kinesthetic language both in this exercise and throughout the focus groups, perhaps indicating that, (at least for the duration of the focus groups), when they think about their family’s mental health experiences, they were focusing on their feelings and sensations. Caregivers used many kinesthetic metaphors such as “got straightened out,” “we went back and forth,” “we felt like . . .,” “a lot of tears,” “slow down,” “it’s so hard,” “drowned my sorrows,” “pulling my hair out,” “burning candles at both ends,” “I want to go jump off a mountain,” “at our wit’s end,”
“spinning our wheels,” “it does start with the parent reaching out,” “gut feeling,” “it was kind of hard,” “my son has gone berserk,” and “stuck in a box,” “like an on and off switch,” “between a rock and a soft place,” “hold onto,” “push them aside,” and “take stabs in the dark.”

Auditory language was next most frequent among caregivers, and included “I have a right to be heard,” and “if you speak up,” “voice your opinion,” and “I tell my story as needed.”

A limited amount of visual language or metaphors used by caregivers was found, including: “not showing him enough affection,” “focused on one child,” “show them their options,” “watching the teachers,” and “I see it happen.” “Take stabs in the dark” is a phrase that was used that uses both kinesthetic and visual language.

Providers also used a great deal of kinesthetic language (“feels as though,” “stand alone,” “untouchable,” “feel normal,” “closed door,” and “I push that”), but did use more Auditory (“they say,” “I say,” “I tell them,” “talk a lot of goals,” “squeezed when things got tight,” “gut reaction,” “saddled with this child,” and “could roll out to be significant”) and Visual language (“showing that,” “pressed against the window,” “to see normal families,” “you see a lot of poverty,” “viewed as scary,” “focus on that,” “paint the big picture,” “see this through,” “let the family see,” “I see that more and more,” and “encourage the family to start looking”) than caregivers.

Interestingly, for both caregivers and providers, much of the kinesthetic language used seems to be representing negative feelings and experiences, while other language, especially visual, seems to be more hope-laden. Perhaps teaching providers to speak to all representational systems, and to move caregivers from (negative) feelings to (positive) vision, will help them better help caregivers ‘get it.’

Images caregivers included in the collage (cut out of popular culture magazines chosen at random) were:

1) [Picture] [Picture] A girl’s face, X-ed out, with the caption “off”.
2) [Picture] A woman teaching a small boy.
3) [Picture] On a deserted island (“all by themselves, and it keeps flooding. just a continual faucet” (“If it is the bills, the school calling, the kids acting up, the behaviors, the partners, everything, just continual and there is just no help around.” (CAREGIVER))
4) [Picture] A lady with her hair standing on end.
5) [Headline] Find yourself between a rock and a soft place.
6) [Picture] Car on its side (an accident with no way out: “your life is always an accident, it just keeps happening. . . . It is always something, it is everyday, you feel like—upside down.” (CAREGIVER))
7) [Picture] A woman putting a raincoat on a small child (“A mother and child communicating. . . . Like a parent that won’t give up, they will keep fighting until they really see the reality come to pass, they hold onto something.” (CAREGIVER))
8) [Headline] I am confident and I am strong.
9) [Headline] Racing past the moon.
10) [Picture] Sponge (“You are absorbing a lot of things that is going on and you are watching a lot of people, you are watching the doctors, you are watching the teachers, you are watching other students, you are watching your friends and your family members and how they treat you and your brain is a sponge and it just absorbs all of these things that is going on around you.” (CAREGIVER))
11) [Headline] Why I fight against—too many friends lost, too many lives destroyed (“advocacy” (CAREGIVER))
12) [Picture] Dog (“It is a dog eat dog world. That is the system.” (CAREGIVER))
13) [Headline] 24-hours (“24-hours a day you are living with it.” (CAREGIVER))
14) [Headline] Blues/Expressions (“If you have occasional blues dealing with everything and that becomes a regular expression for the most part unless you are able to get out and have that balance where you can laugh and the kids have respite and you can go out and take a break and come back and deal with it.” (CAREGIVER))
15) [Headline] Starting over and over.
16) [Picture] Baby doll in the palm of a hand (“Tiny miracle, sometimes when their child is born they look at it as a miracle but when they find out something is wrong, they think it is a disaster and it is still a miracle.” (CAREGIVER))
17) [Picture] A man shaking his fist (“I can really deal with this.” (CAREGIVER))
18) [Headline] Uttermost.
19) [Headline] Sponge.
20) [Headline] Don’t let symptoms stand in the way (“99% of providers let the symptoms stand in the way of trying to help the child.” (CAREGIVER))
21) [Headline] From dress to reality.
22) [Headline] I am confident. I am strong.
23) [Headline] Question? We’ve got answers.
24) [Headline] How can we bridge the financing gap?
25) [Headline] Choosing targets.
26) [Written in] I was just about to believe its ours.
27) [Written in] My mind how can I stop it!
28) [Written in] Talk to one another it’s great.
29) [Written in] Love without home is no home.
30) [Written in] We need help.
31) [Written in] Love reach mountains.
32) [Written in] They really there help me I got to!
33) [Written in] I can really learn if you help just be patient with me.
34) [Written in] Life is great!
35) [Headline] Better-worse.
36) [Headline] Mistakes.
37) [Headline] Interesting. Happy. Successful.
38) [Picture] Family smiling.
39) [Picture] Perfectly made bed.
40) [Picture] Sad looking woman holding a baby.
41) [Picture] Angry looking man.
42) [Picture] Man with numbers swirling around his head.
43) [Picture] A baseball pitcher.
44) [Headline] Finding family ties.
45) [Picture] Children laughing.
46) [Picture] A woman running with the headline “secrets of super-powerful women.”
47) [Picture] A costumed man making a heart sign out of his fingers.
48) [Picture] A woman in combat with the headline “wanted: leadership that
1) [Picture] A corner-mounted shelf (“It is like a huge problem that is mounted here, so it is like a huge something that he is pondering how to overcome it.” (PROVIDER))

2) [Headline] Mothers to blame.

3) [Picture] A huge castle.

4) [Picture] A plate of food.

5) [Picture] Hair wrapped around a paperclip.

6) [Picture] A bottle of scotch.

7) [Picture] A bird flying over a mountain.

8) [Picture] A child catching a baseball.

9) [Picture] A brain scan.

10) [Picture] Lit birthday candles.

11) [Picture] A woman talking on the phone with the headline “busy”.

12) [Headline] New beginnings.

13) [Picture] Doctor in lab coat.

14) [Picture] Man with strange feet.

15) [Picture] Man in prison uniform.

16) [Picture] Mom struggling with her son (“talking about part of the future.” (PROVIDER))

17) [Headline] Escape (“It looks like this family they have hardly anybody and then some families don’t know how to get it, so sometimes some of them try to get out of here which could be a problem, plans an escape. So they are trying to escape from their problems.” (PROVIDER)) – Note that both provider groups chose this identical image.

18) [Picture] A bridge made of hands (“Here is a little boy and his mother who are trying to solve their problems by reaching out to each other, holding hands and going through whatever issues they have together.”) (PROVIDER)

19) [Picture] Child and woman holding hands.

20) [Picture] People teaching a group of children.

21) [Picture] A man clapping his hands, smiling, with the headline “You don’t need the sun to shine.”

22) [Picture] A woman looking up from a computer.

23) [Picture] A man running.

24) [Headline] At the end of the day, the problem is their inability or unwillingness to look in the mirror and ask, ‘what’s wrong here?’

26) [Picture] A woman with an umbrella.
27) [Picture] A woman teaching a young boy.
28) [Picture] A group of women whispering to each other.
29) [Picture] A face of a small girl with the headline “Life insurance isn’t for the people who die. It’s for the people who live.”
30) [Headline] Pricey stinks (“The inability to really get what your kids need because of just lack of money and resources.” (PROVIDER))
31) [Headline] Dreams are good. Realities are.
32) [Picture] A man looking at a scorched earth with the headline “Our greatest challenges. How will you deal with it?”
33) [Picture] A person bent over, washing a floor.
34) [Drawn in] A child in a tunnel (“This little boy or girl who feels like he is in a tunnel and he is very isolated and barricaded in from all his friends or people that he sees on the outside of this little tunnel here that are happy-go-lucky and he is feeling isolated and locked in.” (PROVIDER))
35) [Drawn in] Family in sunshine with a winding road (“This family here is feeling the sunshine of the day and how happy they are and on their way to school whereas this little kid knows he needs medical intervention in order to get here and the path is just long and winding and has a lot of trouble getting to this illusive doctor.” (PROVIDER))
36) [Picture] Girl looking out the window (“she is looking out as though she is isolated and unable to join them.” (PROVIDER))
37) [Picture] Person with lots of arms (“Everybody is sort of grabbing hold and yanking. . . . What do you need now, grab on, hang with me, you are broke again.” (PROVIDER))
38) [Picture] Stressed face (“It is not easy, it doesn’t feel safe all the time. . . not always fun, definitely not free. . . . Sometimes I am at my craziest, that I can beat the odds.” (PROVIDER))
39) [Picture] Helmet (“Always having to be vigilant.” (PROVIDER))
40) [Picture] Blurred picture of car moving fast (“Oftentimes in families things are just really blurred, but also speeding up sometimes real fast.” (PROVIDER))
41) [Picture] A picture of a mouth inside an eye (“This just looks crazy.” (PROVIDER); “That is a feeling that I think a lot of people really get, . . . an almost disintegrated individual as things concerned with the mouth inside an eye, so that you really lost a lot.” (PROVIDER); “You just have to be all seeing, you have to see everything, if something slips by you.” (PROVIDER))
42) [Picture] A child in daddy’s arms (“A lot of love, a lot of support, and your future can be very, very, very good and beautiful.” (PROVIDER))

These images could be used in message interventions to attract attention and communicate key issues at a glance as they lead the message receiver to further explore the intervention (open the brochure, watch the video, attend a workshop, etc.).

**Channels of information**

Preferred information channels were obtained from the results of the card sort of alternate channels of communication. The top choices for caregivers for messages
targeted to themselves included: brochures from the provider’s office; TV show; e-mail; web sites; DVD/video; magazine articles; workshops; and support groups.

Caregiver participants thought that websites were effective because they would provide a great deal of information that can be accessed at the caregiver’s convenience:

“E-mailing is pretty good and the website, because a lot of these sites I sign up for updates and that helps me either with my family or a family I know that is going through all of this, I will print it out and say, hey, did you know about this, or give them the website so that they can go on, so I think the website and emailing.” (CAREGIVER).

DVDs and videos were considered convenient (“you could watch whenever is convenient for you and your family” (CAREGIVER)), creative and entertaining, and informative (“A DVD would be good, that parents that can see something, even like a movie type of thing or maybe something that could entertain them in a way that was creative, they could see it at home and just be taught all of these things or have one CD or video online and another video.” (CAREGIVER); “The best way I think would be in a magazine, or like a DVD, like a short story or something like that about families in these situations and then the person looking at it [would say] yes, that is kind of like my situation, you know at the end of the movie, have them call this number at such and such site or something like that to reach different people.” (CAREGIVER)).

Magazine articles are accessible (“Some people won’t have the accessibility to the internet and e-mails and all.” (CAREGIVER)). Workshops and support groups were considered informative. Participants also suggested that support groups provide two-way communication and support (“Sometimes like with me, you need somebody to talk to because you know there may be somebody in that group is going through what you are going through. . . .” (CAREGIVER); “When you are talking with people, it makes it easier to share that.” (CAREGIVER)).

Provider participants liked the idea of being trained on improving their own mental health literacy and helping caregivers be more literate consumers via DVDs, workshops, websites, newsletters, brochures, and posters. Providers also suggested more interactive training, including coaching and interactive feedback sessions, including a "competency toolbox" encompassing the different domains of mental health literacy (“resource of the day.”) Other suggestions included a mental health concern helpline for general questions:

“I think you really have to almost start with a workshop, you have to have some relationship, I mean it has to be really an interactive thing and then you can send out follow-up supervisory meetings, send out your missionaries to follow up in groups because a lot of these things aren’t just flat information as we discussed, they are sort of an interaction and required discussion about cases. It could have a journal articles, but you could have a website or workbook both that is kind of dedicated to having different segments or chapters that reinforce the curriculum with exercises. I think of a curriculum.” (PROVIDER).

“I think the main thing would be that for folks where it would help to go through the same material twice to record the class and the workshop.” (PROVIDER)
“In one of my past jobs . . . it was my job to teach young doctors how to communicate with patients in a way that was trusting, respectful, did all these things and they were required to submit a couple of videotapes a year where they would get critiqued in how well, and it was so helpful that without that, you could talk until you were blue in the face and because they didn’t pick up on some of the non-verbals, they didn’t pick up on them when they were tired, they came across like an ass. . . . And then it was very helpful to have small group discussions about where they would commit to one aspect that they would work on, so there is a lot of literature in the medical profession, particularly in physician training” (PROVIDER)

Participants also suggested providing children’s books for children with mental, emotional, and behavioral disorders; their siblings; and other children; as well as textbooks for elementary, middle school, and high school kids; and materials for churches; to explain mental health issues to them.

Conclusions

This paper has suggested key messages to be included in communication interventions designed to improve mental health literacy among caregivers and providers and has identified several potential communication channels.

Many of the messages suggested for our literacy intervention are fairly straightforward and clear, and could likely be effectively communicated through channels such as posters or brochures. These messages might include: Caregivers have the right to be heard by their child’s providers; the opinions of the caregiver and the child are important; and mental, emotional, and behavioral problems do not make a child less valuable.

Some messages are more complex and may be most effectively communicated through channels of moderate richness such as DVDs. These messages might include: mental, emotional, and behavioral problems in a child may be a mental health and not a discipline issue; how to find out what services are available; how to get a child tested.

Finally, complex messages may involve teaching caregivers decision making or other complex skills and should be conveyed through a rich media such as one-on-one counseling, training, or coaching. These messages might include: how to balance the risks and benefits of medication; how to make placement decisions for a child; how to ask for help, services, treatment, and resources in a way that the child and family get what they need.

Provider-directed messages should be delivered via multi-channeled media such as training, coaching, and/or workshops, and they would address topics such as how to assess a child’s behaviors as well as the needs of families and caregivers; help families pay for services; identify treatment and service options; develop a therapeutic relationship with families and caregivers; and make placement decisions. In addition, provider training could include “train-the-trainer” information on how to help their families: ask for help; be a good parent; maintain hope; know their rights; and make medication decisions. Provider messages would use a combination of kinesthetic, auditory, and visual language.
Caregiver-directed messages should include a combination of hands-on role playing, one-on-one coaching to work from feelings, emotions, and sensory input, and also website and DVDs for follow-up messages. Caregiver messages would include topics on practical tips such as surviving the family’s problems; helping make things better for their family; how to make medication decisions; how to make placement decisions; how to ask for help in a useful manner; and how to be a good parent to all their children. They would also address caregiver rights such as the right to be heard by the provider. In addition, they would address beliefs such as their and their child’s opinions are important; and mental, emotional, and behavioral problems do not make their child less valuable and can be mental health-related rather than discipline problems. Caregiver messages would use kinesthetic, auditory, and visual language, but would be weighed more heavily on kinesthetic language. Visual language should be used to move the attitudes from the negative to the hopeful and positive.

The results of our continuing research on mental health literacy have two major implications for mental health service policy and planning. First, this research helps define the concept of mental health literacy and its role in contributing to service utilization, service compliance and consumer driven services. Caregiver-based participation is a critical element of system of care (SOC) principles that emphasize individualized, family-focused, community-based, and culturally competent care (Stroul & Friedman, 1986). This research suggests strategies for communication interventions that will enhance the mental health literacy levels of caregivers and providers.
References


## Appendix A

### Mean Scores for Variable in the Five Subscales for Providers

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Mean</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>BVC:</strong> Having mental, emotional, and/or behavioral problems does not make a child less valuable to society.</td>
<td>4.97</td>
<td>.186</td>
</tr>
<tr>
<td><strong>BVC:</strong> The opinions of the families I work with are important.</td>
<td>4.86</td>
<td>.441</td>
</tr>
<tr>
<td><strong>BVC:</strong> Despite their problems, the families I work with are people who are worth helping.</td>
<td>4.76</td>
<td>.511</td>
</tr>
<tr>
<td><strong>BVC:</strong> People can live a normal life despite having mental illness.</td>
<td>4.66</td>
<td>.614</td>
</tr>
<tr>
<td><strong>BVC:</strong> Mental illness is treatable.</td>
<td>4.66</td>
<td>.670</td>
</tr>
<tr>
<td><strong>BVC:</strong> The families I work with have many strengths that enhance their health and well being.</td>
<td>4.62</td>
<td>.622</td>
</tr>
<tr>
<td><strong>BVC:</strong> I am capable of helping the families I work with improve their situation.</td>
<td>4.45</td>
<td>.686</td>
</tr>
<tr>
<td><strong>BVC:</strong> The families I work with, overall, are open with me.</td>
<td>4.24</td>
<td>.511</td>
</tr>
<tr>
<td><strong>BVC:</strong> The families I work with genuinely want my help.</td>
<td>4.03</td>
<td>.778</td>
</tr>
<tr>
<td><strong>BVC:</strong> Generally, the families I work with are capable of complying with my treatment or advice.</td>
<td>4.03</td>
<td>.680</td>
</tr>
<tr>
<td><strong>BR:</strong> The families I work with have the right to be treated with respect.</td>
<td>4.97</td>
<td>.186</td>
</tr>
<tr>
<td><strong>BR:</strong> The children I work with have the right to receive an education regardless of their problems or needs.</td>
<td>4.93</td>
<td>.258</td>
</tr>
<tr>
<td><strong>BR:</strong> The families I work with have to right to ask for help when they need it.</td>
<td>4.90</td>
<td>.310</td>
</tr>
<tr>
<td><strong>BR:</strong> The caregivers I work with have the right to ask me questions about their child’s care.</td>
<td>4.90</td>
<td>.310</td>
</tr>
<tr>
<td><strong>BR:</strong> The caregivers I work with have the right to choose their child’s services (except when their services are court-mandated).</td>
<td>4.90</td>
<td>.310</td>
</tr>
<tr>
<td><strong>BR:</strong> The families &amp; caregivers I work with have the right to question my decisions.</td>
<td>4.83</td>
<td>.384</td>
</tr>
<tr>
<td><strong>BR:</strong> The caregivers I work with have the right to ask for all the services they need.</td>
<td>4.83</td>
<td>.384</td>
</tr>
<tr>
<td><strong>BR:</strong> The families I work with have the right to receive any psychological, mental, or physical testing they require.</td>
<td>4.79</td>
<td>.774</td>
</tr>
</tbody>
</table>
BVC: Having mental, emotional, and/or behavioral problems does not make a child less valuable to society.  
29 4.97 .186

BVC: The opinions of the families I work with are important.  
29 4.86 .441

BVC: Despite their problems, the families I work with are people who are worth helping.  
29 4.76 .511

BVC: People can live a normal life despite having mental illness.  
29 4.66 .614

BVC: Mental illness is treatable.  
29 4.66 .670

BVC: The families I work with have many strengths that enhance their health and well being.  
29 4.62 .622

BVC: I am capable of helping the families I work with improve their situation.  
29 4.45 .686

BVC: The families I work with, overall, are open with me.  
29 4.24 .511

BVC: The families I work with genuinely want my help.  
29 4.03 .778

BVC: Generally, the families I work with are capable of complying with my treatment or advice.  
29 4.03 .680

BR: The families I work with have the right to be treated with respect.  
29 4.97 .186

BR: The children I work with have the right to receive an education regardless of their problems or needs.  
29 4.93 .258

BR: The families I work with have to right to ask for help when they need it.  
29 4.90 .310

BR: The caregivers I work with have the right to ask me questions about their child's care.  
29 4.90 .310

BR: The caregivers I work with have the right to choose their child's services (except when their services are court-mandated).  
29 4.90 .310

BR: The families & caregivers I work with have the right to question my decisions.  
29 4.83 .384

BR: The caregivers I work with have the right to ask for all the services they need.  
29 4.83 .384

BR: The families I work with have the right to be heard by me.  
29 4.66 .721

COMM: I am capable of conveying information to the families I work with so that they understand what I'm telling them.  
29 4.72 .455

COMM: I am able to communicate with the families I work with in ways that are culturally competent.  
29 4.62 .494

BR: The families I work with have the right to receive any psychological, mental, or physical testing they require.  
29 4.79 .774
<table>
<thead>
<tr>
<th>Rating</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.59</td>
<td>COMM: The therapeutic relationship I have with the families I work with facilitates communication, self-disclosure, and information-exchange between us.</td>
</tr>
<tr>
<td>4.45</td>
<td>COMM: I am able to read the non-verbal communication of the families I work with to obtain more information about their condition or situation.</td>
</tr>
<tr>
<td>4.41</td>
<td>COMM: I am able to listen to the families I work with talk about their symptoms so that I can make diagnosis/assessment decisions from their information.</td>
</tr>
<tr>
<td>4.66</td>
<td>CB: I am able to decide when a family's home is or is not safe for me to visit.</td>
</tr>
<tr>
<td>4.66</td>
<td>CB: I am able to decide when, where, and how it is appropriate to refer families to other professionals and/or treatment options.</td>
</tr>
<tr>
<td>4.62</td>
<td>CB: I am able to decide when it is appropriate to call in child welfare officials for the families I work with.</td>
</tr>
<tr>
<td>4.55</td>
<td>CB: I am able to make referral decisions about the families I work with.</td>
</tr>
<tr>
<td>4.28</td>
<td>CB: I am able to make decisions about treatment recommendations for the families I work with.</td>
</tr>
<tr>
<td>4.07</td>
<td>CB: I am able to make diagnosis or assessment decisions about the families I work with.</td>
</tr>
<tr>
<td>4.45</td>
<td>FB: I know what mental health resources and services are available in the community for the families I work with.</td>
</tr>
<tr>
<td>4.41</td>
<td>FB: I am able to help the families I work with help themselves.</td>
</tr>
<tr>
<td>4.41</td>
<td>FB: I know how to access the resources, services and treatments in this community for the families I work with.</td>
</tr>
<tr>
<td>4.34</td>
<td>FB: I am able to match my recommendations to the situation (financial, capability, lifestyle, etc.) of the families I work with.</td>
</tr>
<tr>
<td>4.10</td>
<td>FB: I can identify alternative treatment options for the families I work with.</td>
</tr>
<tr>
<td>4.07</td>
<td>FB: I am able to help the families I work with figure out how to pay for treatments/services/medications.</td>
</tr>
<tr>
<td>3.83</td>
<td>FB: I can understand or comprehend what it's like to be a caregiver for a child with a mental disorder.</td>
</tr>
<tr>
<td>3.66</td>
<td>FB: I know when a child I work with needs medication and when he/she does not.</td>
</tr>
<tr>
<td>Dependent Variable:</td>
<td>2</td>
</tr>
<tr>
<td>--------------------</td>
<td>---</td>
</tr>
<tr>
<td>Knowledge Sub-domain</td>
<td></td>
</tr>
<tr>
<td>Agency Sub-domain</td>
<td></td>
</tr>
<tr>
<td>Control Sub-domain</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Independent Variables:</th>
<th>Marginal Effects</th>
<th>Robust z-score</th>
<th>Marginal Effects</th>
<th>Robust z-score</th>
<th>Marginal Effects</th>
<th>Robust z-score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low Organization MH Literacy (omitted)</td>
<td>-----</td>
<td>------</td>
<td>-----</td>
<td>------</td>
<td>-----</td>
<td>------</td>
</tr>
<tr>
<td>Middle Organization MH Literacy</td>
<td>0.997</td>
<td>-0.039</td>
<td>-0.120</td>
<td>-0.533</td>
<td>-1.990</td>
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<tr>
<td>High Organization MH Literacy</td>
<td>1.000</td>
<td>15.260**</td>
<td>0.175</td>
<td>0.620</td>
<td>-0.474</td>
<td>-2.490</td>
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<tr>
<td>Less than High School (omitted)</td>
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<td>------</td>
<td>-----</td>
<td>------</td>
<td>-----</td>
<td>------</td>
</tr>
<tr>
<td>High School</td>
<td>0.004</td>
<td>0.080</td>
<td>-0.366</td>
<td>-1.200</td>
<td>-0.265</td>
<td>-0.970</td>
</tr>
<tr>
<td>College</td>
<td>0.092</td>
<td>1.750*</td>
<td>-0.041</td>
<td>-0.190</td>
<td>-0.218</td>
<td>-1.000</td>
</tr>
<tr>
<td>Female</td>
<td>0.036</td>
<td>0.910</td>
<td>0.236</td>
<td>1.220</td>
<td>0.315</td>
<td>1.070</td>
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<tr>
<td>Black</td>
<td>-0.004</td>
<td>-0.080</td>
<td>0.223</td>
<td>0.720</td>
<td>0.476</td>
<td>2.050**</td>
</tr>
<tr>
<td>Other Race</td>
<td>0.092</td>
<td>0.670</td>
<td>0.188</td>
<td>0.560</td>
<td>0.791</td>
<td>3.430**</td>
</tr>
<tr>
<td>Hispanic</td>
<td>-0.061</td>
<td>-1.590</td>
<td>-0.266</td>
<td>-1.540</td>
<td>-0.611</td>
<td>-3.960**</td>
</tr>
<tr>
<td>Age</td>
<td>-0.013</td>
<td>-1.140</td>
<td>0.197</td>
<td>1.880*</td>
<td>0.015</td>
<td>0.330</td>
</tr>
<tr>
<td>Age Squared</td>
<td>0.000</td>
<td>1.410</td>
<td>-0.002</td>
<td>-1.670*</td>
<td>0</td>
<td>-0.440</td>
</tr>
<tr>
<td>Health Status: Very Good/Excellent</td>
<td>-0.036</td>
<td>-1.170</td>
<td>0.318</td>
<td>1.820*</td>
<td>0.098</td>
<td>0.430</td>
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<tr>
<td>Married</td>
<td>0.050</td>
<td>1.300</td>
<td>0.198</td>
<td>1.150</td>
<td>0.201</td>
<td>1.080</td>
</tr>
<tr>
<td>Covered by Medicaid</td>
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<td>1.240</td>
<td>0.384</td>
<td>2.100**</td>
<td>0.087</td>
<td>0.500</td>
</tr>
<tr>
<td>Years receiving service for child ≥ 1 year</td>
<td>-0.037</td>
<td>0.630</td>
<td>-0.495</td>
<td>-2.020**</td>
<td>-0.422</td>
<td>-1.520</td>
</tr>
<tr>
<td>Caregiver ever received MH services</td>
<td>0.021</td>
<td>0.520</td>
<td>0.062</td>
<td>0.370</td>
<td>-0.437</td>
<td>-2.100**</td>
</tr>
</tbody>
</table>

Number of Observations: 50 50 50

Pseudo R²: 0.344 0.335 0.473

** Significant at the 5 percent, two-tail level
* Significant at the 10 percent, two-tail level