Developing a Multiple **Caregiver** Group for Caregivers of Adolescents with Disruptive

Behaviors

Running Head: DEVELOPING A MULTIPLE FAMILY GROUP

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Abstract

This article describes the development of a 6-week **multiple caregiver group** intervention for primary caregivers of adolescents diagnosed with Oppositional Defiant Disorder or Conduct Disorder in low-income African American families. The intervention is aimed at increasing the primary caregivers' self-efficacy in managing interactions within the family and especially with child serving educational, mental health, juvenile justice, and child welfare systems. Development of the intervention involved seven iterative activities performed in a collaborative effort between an interdisciplinary academic team, community engagement specialists, members of the targeted population, and clinical partners from a large public mental health system. The intervention development process described in this article can provide guidance for teams that aim to develop new mental health interventions that target specific outcomes in populations with unique needs.

Keywords: oppositional defiant disorder, conduct **disorder, multiple caregiver groups, intervention development, caregiver and child serving systems**

Developing a **Multiple Caregiver Group** for Caregivers of Adolescents with Disruptive Behaviors

Caregivers of adolescents who are diagnosed with Oppositional Defiant Disorder (ODD) and/or Conduct Disorder (CD) experience significant challenges (Author et al., 2015; Viana et al., 2013). ODD/CD are serious mental disorders, which are generally diagnosed first during childhood (Frick & Dickens, 2006; Nock, Kazdin, Hiripi, & Kessler, 2007). ODD is characterized by an angry/irritable mood and defiant, negative, and hostile behaviors, while CD is characterized by a pattern of aggressive and destructive behaviors and serious violations of rules (Frick & Dickens, 2006; Nock et al., 2007). **In the United States, 10% of adolescents 13 to 18 years of age are diagnosed with ODD/CD and account for half of all child referrals to outpatient mental health clinics (Handwerk, Field, Dahl, & Malmberg, 2012; Merikangas et al., 2010). The median age of onset of these behavior disorders is 11 years, with some children being diagnosed much earlier, and the severity of the illness typically intensifies as the child gets older (Merikangas et al., 2010).**

Adolescents with ODD/CD, compared to younger children, pose particular challenges for primary caregivers because of increasing physical size and strength, need for autonomy, peer pressure, and risk-taking behaviors (Steinberg, 2007). Adolescents with ODD/CD are at risk for **negative outcomes such as** poor educational achievement, substance abuse, and involvement with the criminal justice system, **and these effects often extend** to adulthood (Conway, Swendsen, Husky, He, & Merikangas, 2016; Heflinger & Humphreys, 2008; Merikangas et al., 2011; Petitclerc & Tremblay, 2009; Sayal, Washbrook, & Propper, 2015).

The primary responsibility of caring for adolescents with ODD/CD is typically assumed by a parent or another adult family member (referred to as the primary caregiver). Primary caregivers often report high levels of stress (Author, Al-Khattab, Knopf, & Mazurcyk, 2014; Author, Gerkensmeyer, Stephan, Wheeler, & Hanna, 2012; Rosenzweig & Kendall, 2008; Shin & Brown, 2015) due to the high demands of managing the adolescents' disruptive behaviors, **often over the course of many years** (Cox, 2003; Author et al., 2014; Author et al., 2012; Rosenwald & Bronstein, 2008; Schneiderman & Villagrana, 2010). Primary caregivers must also manage frequent interactions with the many child serving systems that provide mental health, educational, child welfare, or juvenile justice services to the adolescent and family (Author et al., 2015; Saunders, 2013; Valenzuela & Smith, 2016). In addition, due to the nature of their adolescents' behaviors, primary caregivers often report experiencing social stigma (Mukolo, Heflinger, & Wallston, 2010). The stress of caring for an adolescent with ODD/CD can lead to the development or exacerbation of a number of negative health outcomes, including anxiety, depression, and physical health problems as well as impairment in the quality of life and disruptions in family functioning (Author et al., 2015; Author et al., 2012; Saunders, 2003).

The challenges of caring for adolescents with ODD/CD are often accompanied by other adversities such as parental drug or alcohol use, parental incarceration, interpersonal violence, neighborhood deterioration, and socioeconomic disadvantage (Alegria, Green, McLaughlin, & Loder, 2015; Copeland, 2006; Grimmett et al., 2016; Author et al., 2015; Sydow, Retzlaff, Beher, Haun, & Schweitzer, 2013). African American (AA) families of adolescents with ODD/CD are especially affected by these adversities due to their overrepresentation in socioeconomically disadvantaged populations (Byck, Bolland, Dick, Ashbeck, & Mustanski, 2013; Grimmett et al., 2016; Simons et al., 2016). Adolescents with ODD/CD in the low-income

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AA families often receive poor quality mental health services, frequently drop out of care, and experience discrimination in their interactions with child serving systems (Alegria et al., 2015; Copeland, 2006; Grimmett et al., 2016; Office of Surgeon General, 2001; McKay & Bannon Jr, 2004).

Several psychosocial interventions such as Multisystemic Therapy and Brief Strategic Family Therapy have been shown to be effective for adolescents with ODD/CD and their families (Burns, Fisher, & Ganju, 2011; Epstein et al., 2015). These interventions teach primary caregivers how to manage the adolescents' disruptive behaviors and improve parent-child interactions. To our knowledge, no published intervention has thus far addressed the stressors of primary caregivers of adolescents with ODD/CD particularly those related to difficult interactions within the family or with child serving systems. To fill this knowledge gap, our research team developed the FAmily Management Efficacy (FAME) intervention for low income AA primary caregivers of adolescents aged 12 to 17 years old and diagnosed with ODD/CD.

The purpose of this article is to describe the development of FAME. The intervention was developed by an interdisciplinary academic research team with backgrounds in nursing, sociology, psychology, and music therapy in collaboration with a variety of community partners. The following activities comprised the intervention development process: (1) conducting a preliminary descriptive study, (2) forming community advisory boards, (3) determining the theoretical basis for the intervention, (4) identifying the primary treatment approach, (5) finalizing the conceptual framework, (6) determining the primary features of the intervention, and (7) identifying the intervention components, including the intervention content and the activities for each session.

Conducting a Preliminary Descriptive Study

Because the research team was initially interested in developing treatment strategies for all family members of adolescents with ODD/CD, we first conducted a preliminary qualitative descriptive study to identify the challenges and needs of **all** family members (i.e., primary caregivers, siblings, and other significant adult caretakers) of AA adolescents with ODD/CD. This study, **which included** semi-structured interviews with 15 adolescents diagnosed with ODD/CD and their family members, including 15 caregivers, 10 other adult family members, and 12 siblings, **has been described in detail elsewhere (Author et al., 2015; Author et al., 2014)**.

Because the interviews revealed that primary caregivers experienced pronounced and unique challenges that were burdensome and unrelenting, **we determined that an intervention was needed for the primary caregivers specifically, and we thus focused on the data they provided**. The two most salient problems they identified were the adolescents' disruptive behaviors and stressful interactions with child serving systems (Author et al., 2015; Author et al., 2014). The primary caregivers were overwhelmed by having to constantly manage the adolescents' aggressive, defiant, and deceitful behaviors and feeling responsible for the adolescents' safety and the safety of others threatened by the adolescents' behaviors. Some primary caregivers had to remain vigilant for fear that the adolescents would engage in dangerous or criminal activities. In addition, the primary caregivers felt burdened by frequent and often unscheduled meetings with child serving systems (e.g., being "called to" school or having the police "show up" at their house). They often felt blamed for their adolescents' behaviors in these meetings, were left out of treatment decisions, and were frustrated by the lack of effective programs and services (Author et al., 2015; Author et al., 2014). The caregivers expressed a desire to meet with others who experienced similar problems and recommended

interventions that focused on family communication, conflict resolution, education about the adolescents' disorder, and strategies to improve interactions with child serving systems (Author et al., 2015; Author et al., 2014).

Forming Community Advisory Boards

We convened two community advisory boards to inform the development of FAME: a Family Advisory Board and a Professional Advisory Board. The Family Advisory Board included five caregivers of AA adolescents with ODD/CD who were recruited from a child and adolescent program of a large publicly funded community mental health center. The Professional Advisory Board included six professionals who worked with the population of interest and were employed by the same mental health center. Members of the Professional Advisory Board included a nurse, a psychiatrist, a counselor in a school-based mental health program, a counselor in a juvenile justice-based mental health program, and a case manager.

The principle author of this study worked with the Indiana Clinical and Translational Sciences Institute Patient Engagement Core to develop facilitation strategies for advisory board meetings. The Patient Engagement Core is an interdisciplinary team that works with investigators to develop robust and collaborative community engagement approaches. With the assistance of Patient Engagement Core graphic, visual, and service design specialists, the research team developed meeting materials to elicit discussions with advisory board members about proposed intervention content, procedures, and targeted outcomes. Prior to each board meeting, the principle author met with the Patient Engagement Core team to review audio recordings and field notes from the previous meeting and to discuss goals for upcoming meetings.

We held two separate meetings of the Family Advisory Board and Professional Advisory Board followed by one joint meeting with both boards. **The attendance rates at these meetings were 100%.** All meetings were facilitated by the principle author. Family Advisory Board members were compensated for their time and travel with a $50 gift card for each meeting attended. Light refreshments were also served at the Family Advisory Board meetings. The Professional Advisory Board members were not compensated for their board membership because meetings were held during regular work hours.

The advisory boards provided critical input for the development of the intervention. The board members confirmed that primary caregivers of AA adolescents with ODD/CD experience multiple and severe stressors and could benefit from an intervention that addressed their major concerns. Both boards recommended that the intervention be conducted in a group format so that primary caregivers could learn and receive support from others who experienced similar challenges. Both boards highlighted the importance of strengthening interactions within the family and with child serving systems. They stressed that in AA communities, families are often comprise of biological or marital relatives such as parents, siblings, uncles/aunts, and grandparents (kin) and intimate family friends (fictive kin). The advisory boards recommended that the intervention include kin and fictive kin to provide support to the primary caregivers.

While it was clear that managing the adolescents' disruptive behaviors was an on-going concern of the primary caregivers, evidence-based interventions have been developed to improve behavioral management strategies (Epstein, Fonnesbeck, Potter, Rizzone, & McPheerters, 2015). In addition, parental strategies for managing the adolescents' disruptive behaviors are often addressed in routine treatment protocols. Therefore, we decided that intervention would focus on increasing the primary caregivers' self-efficacy in managing interactions within the family and

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especially with child serving systems with the long-term goal of decreasing caregiver stress and improving their quality of life.

Determining the Theoretical Bases for Intervention

Network Episode Model. Based on the literature review, information from our preliminary study, and recommendations from the advisory boards, the research team decided to ground the intervention in the Family-Based Network Episode Model of Access to Child Mental Health Services [F-NEM] (Costello, Pescosolido, Angold, & Burns, 1998). This child-targeted version of the more general NEM (Pescosolido, 1991) was developed to understand how recognition and response to mental health problems and associated challenges are embedded in family and community cultures (Copeland, 2006). The NEM posits that individuals' perceptions, beliefs, and behaviors about important life and mental/health matters are facilitated or hindered by important others in their social network. The F-NEM **indicates that** pathways to care, adherence **to care**, and **care** outcomes of families with children who experience mental health problems **are shaped by the families' social networks**. A review of literature revealed that mental health interventions that strengthen social networks within and outside families buffer stress and improve the quality of life (Gerkensmeyer, Perkins, Scott, & Wu, 2008; Luszczynska, Scholz, & Schwarzer, 2005; McKay et al., 2011). **The decision to develop a group rather than individual intervention and to include kin were based on the assumption drawn from the F-NEM that the strengthening of social networks has the potential to improve intervention outcomes.**

Social Cognitive Theory. Because improving primary caregiver self-efficacy is a goal of the intervention, the research team also drew on several constructs from Bandura's Social Cognitive Theory (Bandura, 1986). Bandura argued that self-efficacy, a persons' perceived

capacity to carry out certain actions, influences the persons' will to begin and sustain a sequence of actions needed to meet their goals. Three constructs from this theory shaped the intervention, particularly as we designed the therapeutic activities of each session. First, an *enactive attainment* paves way for the successful performance of a desired action. Second, *vicarious information* is derived from observing the successful performance of another. Third, *verbal persuasion* includes remarks made by others that suggest a person has the capacity to carry out a desired behavior. **Research shows that individuals with higher general self-efficacy have lower levels of stress and higher quality of life (Cramm, Strating, Roebroeck, & Nieboer, 2013).**

**Identifying the Primary Treatment Approach**

Problem-solving therapy. While F-NEM (Costello et al., 1998) provided the theoretical basis for the intervention, the team chose to incorporate strategies from Problem-Solving Therapy to deliver the intervention. Problem-Solving Therapy is a transdiagnostic approach that helps persons deal effectively with real-life problems (Nezu, Nezu, & Colosimo, 2015). Problem-Solving Therapy is based on a diathesis-stress model of psychopathology, which suggests that a variety of biological, psychological, and sociocultural factors influence persons' vulnerabilities to stress and social problem-solving abilities. The aim of Problem-Solving Therapy is to foster the development of adaptive problem-solving attitudes and behaviors in order to reduce distress and improve well-being. Problem-Solving Therapy focuses on persons' problem orientation, which includes their cognitive-affective schema about life problems and their ability to cope with such problems, and their problem-solving style, which includes the cognitive-behavioral activities that they use to solve everyday problems (Nezu et al., 2015). **The**

approach has been shown to be effective for treating a variety of psychological disorders (Bell & D'Zurilla, 2009; Malouff, Thorsteinsson, & Schutte, 2007).

Finalizing the Conceptual Framework of the intervention

The research team finalized the conceptual model (Figure 1) for the intervention based on the results of the activities described above. The **antecedents that serve as the targets of change by the intervention include primary caregiver stress resulting from problematic interactions within the family and especially with child serving systems. We developed the intervention to improve primary caregiver communication and problem-solving skills related to these antecedents; to improve the primary caregiver's sense of self-efficacy; and to increase the size and density of their social network. We anticipate that while the intervention will have a direct effect on these factors, it will also have a direct and mediated effect on the distal outcomes of caregiver perceived stress and quality of life and family functioning.**

Figure 1. Conceptual Framework for the Intervention
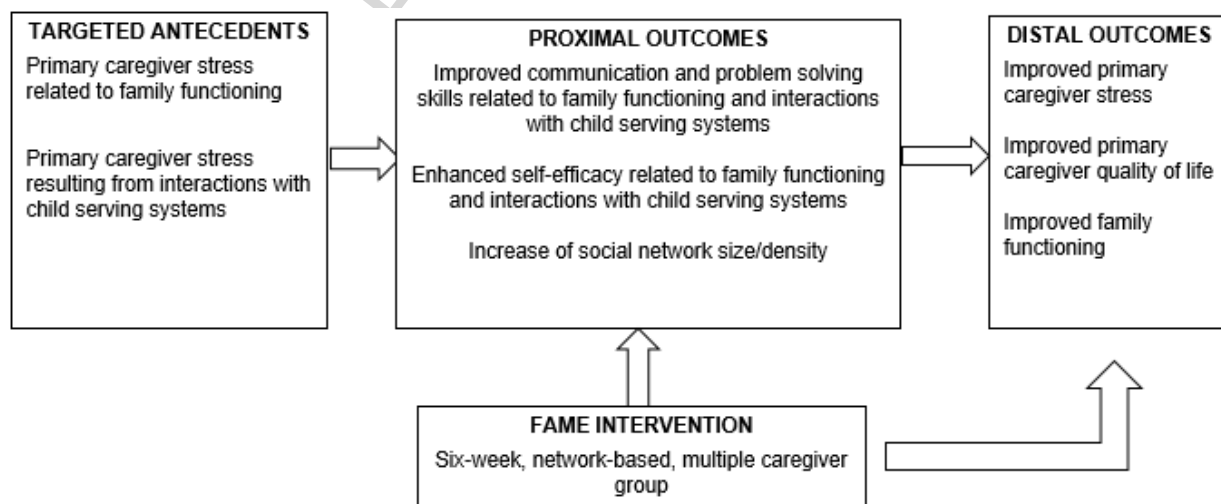
Determining the Primary Features of the Intervention

Delivery modality. We determined that the intervention would be offered as a **multiple caregiver group** intervention, which was advocated strongly by participants in our preliminary study and members of our advisory boards. **The group modality will** provide primary caregivers a chance to share their stories and learn from one another's challenges and successes. **Such groups have the advantage of bringing together persons with similar lived experiences to offer them an opportunity to support and learn from one another** (Chacko et al., 2015; Fristad, Gavazzi, & Mackinaw-Koons, 2003; Gopalan, 2016; Gopalan et al., 2015; McDonell & Dyck, 2004; McKay et al., 2011). For example, a multiple family group approach for children (7 to 12 years) diagnosed with ODD/CD and their family members was shown to decrease oppositional behaviors and improve family functioning (Chacko et al., 2015; McKay et al., 2011). **Because no such groups have focused on primary caregivers' stressors resulting from interactions with child serving systems, we** determined **our intervention** would be delivered as a 2-hour weekly **group** session over a period of six consecutive weeks. We reasoned that weekly sessions would leverage therapeutic momentum and minimize dropout. Moreover, we determined that each target group would consist of 12 participants with at least six caregivers and six **kin/fictive kin**. This size group enhances effective management of group dynamics, provides ample opportunity for discussion, and allows for optimal engagement in intervention activities (Stewart, Usher, & Allenby, 2009).

Group composition. Each primary caregiver was required to bring one kin/fictive kin to offer support. The intervention was designed to include kin and fictive kin who agreed to

accompany primary caregivers to group meetings **as these individuals** are critically important to families in the AA communities (Copeland, 2006; Grimmett et al., 2016). We presumed that the inclusion of kin/fictive kin could lessen the caregivers' feelings of isolation as well as provide instrumental and emotional support. We view kin/fictive kin as "cheerleaders" for the primary caregivers in stressful situations.

Group facilitators. Given the sensitivity of the intervention content, and the possible vulnerabilities of participants, the team determined that the intervention sessions would be facilitated by a lead facilitator with at least a Master's degree in a mental health profession, experience working with families with adolescents diagnosed with ODD/CD including AA families, and group facilitation skills. The sessions would also have a co-facilitator who had at least a Bachelor's degree in a mental health profession. The facilitators would receive extensive training for effective delivery of the intervention.

Identifying the Components of the Intervention

Intervention content. Content of the intervention sessions was designed to improve the self-efficacy of primary caregivers that in turn will enhance interactions within the family and with child serving systems. Six sessions were designed with each session focusing on a different topic. The first session aims to develop group cohesion and introduce the structure and activities of the intervention to the group. The second session focuses on improving interactions within the family, and sessions three through five each focus on improving interactions with a different child serving system. The sixth session is dedicated to developing a plan to manage stress. Table 1 displays the focal content of each session and the rationale for each topic.

Table 1

FAME Intervention Content

Focal topics of FAME sessions	Focal Topic	Rationale
Session 1	Letting It All Out	Introductory activities help develop group cohesion and orient members to the structure and processes of the group.
Session 2	Strengthening Family Interactions	Interactions within the family often increase the stress of primary caregivers.
Session 3	Strengthening Child Service Interactions: Mental Health	Primary caregivers do not feel included in their adolescents' treatment, have unanswered questions about their adolescents' treatment plans, and can feel blamed for the adolescents' behaviors (Author et al., 2015; Author et al., 2014)
Session 4	Strengthening Child Service Interactions: School	Primary caregivers often feel burdened by being frequently "summoned" to meetings at school and receiving frequent urgent contacts from teachers or other school personnel related to the adolescents' disruptive behaviors in school (Author et al., 2015; Author et al., 2014).
Session 5	Strengthening Child Service Interactions: Juvenile Justice	Primary caregivers of adolescents with ODD/CD are often distressed by the adolescents' involvement with law enforcement (e.g., dread of the police coming to the house) and the juvenile justice system (e.g., having their adolescents incarcerated). They often feel blamed and are embarrassed by these interactions (Author et al., 2015; Author et al., 2014).
Session 6	Remember Your Needs	Primary caregivers experience high degrees of stress and often disregard their own health and well-being due to the challenges of caring for their adolescents' and other life adversities.

Intervention activities. All six sessions of the intervention follow a similar format. The activities are designed based on constructs drawn from Social Cognitive Theory (Bandura, 1986) and principles of Problem-Solving Therapy (Nezu et al., 2015). These activities and examples are described in Table 2. This table was developed for illustrative purposes and does not represent real group events. The examples are drawn from the stories of participants from our preliminary study, the authors' clinical experiences, and discussions with collaborators. Sheets

with tips and homework assignments are given at the end of each session to reinforce learning.

Tips sheets provide recommendations for interacting with child serving systems. They are one or

two pages long and are worded in everyday terms with colored photo captions focused on the

session topic. Tips sheets include examples such as "*Interacting Effectively with Mental Health*

Professionals," "*Parents and Schools – Things to Think About,*" "*Tips for Effectively Handling*

a Crisis Situation," and "*Remembering Your Needs: Self-Care Tips.*" Homework focuses on

integrating lessons learned in the group sessions into participants' daily routines. The

participants' experiences with the homework are reviewed during the subsequent session.

Table 2

FAME Intervention Activities

Group Activities	Description	Rationale	Example (Session **4 Strengthening Child Service Interactions: School**)
Information-sharing	Facilitators provide general information about the focal topic of the week	Provides context for each session	Facilitators provide information about common stressors primary caregivers experience in interactions with schools
Participatory/ experiential learning	Facilitators encourage participants to share personal stories relevant to focal topic	Enables participants to identify their problem orientation and problem-solving style (Nezu et al., 2015) Provides vicarious information about others' successful problem-solving (Bandura, 1986; Kane et al., 2007;	Participants share their experiences in interacting with school personnel. Two participants commiserate about not having a social life because they are "always at the school." Two other participants share how they have petitioned for in-school mental health services for their adolescents.

		Wittkowski et al., 2016)	
Role playing/skills building	Facilitators structure role plays based on participants' case scenarios with special emphasis on use of effective problem-solving steps.	Enables enactive attainment (Bandura, 1986; Kane et al., 2007; Wittkowski et al., 2016)	Facilitator and participant role play how to handle interactions with a teacher who insists the participant leave work to attend a mandatory disciplinary meeting when leaving work might cost the participant her job.
Small group sharing and feedback	Participants split into groups of 3 caregivers and kin/fictive kin. Each participant shares a problem and their response to the problem, reflects on the effectiveness of their response, and receives feedback from others about alternate effective responses.	Enables verbal persuasions (Bandura, 1986; Kane et al., 2007; Wittkowski et al., 2016)	One participant reveals how she was not informed of her adolescent's in-school suspension and how she "lost it" when she finally had a meeting with the teacher. Other group members support her right to be informed about the suspension and suggest a variety of ways she might phrase a request to the teacher that she be informed of any disciplinary actions in the future.

Discussion

This article describes development of FAME, a 6-week group intervention for primary

caregivers of adolescents aged 12 to 17 years in low-income AA families who are diagnosed

with ODD/CD. The intervention development process described here can provide guidance for

teams aiming to develop new mental health interventions that target specific outcomes in

populations with unique needs. Each activity was essential in developing an intervention that is

theoretically based, acceptable to the target population, feasible for delivery in community

mental health settings, culturally informed, and effective in addressing the targeted outcomes.

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The development of the intervention involved a multitude of decisions made systematically and collaboratively. Each of the groups involved - a multidisciplinary academic research team, community engagement specialists, members of the targeted population, and clinical partners from a large public mental health program - contributed a unique perspective to the intervention design.

The next step for our research team is to conduct a pilot study to examine the feasibility and acceptability of the intervention and to obtain estimates of the preliminary effects of the intervention on self-efficacy, problem solving skills, stress, quality of life, family functioning, and social network size/density. The pilot study is in progress. Once completed, we will use findings to modify intervention as indicated before conducting a larger randomized clinical trial.

Our long-term goal is to develop an intervention that could be widely adopted in clinical practice to mitigate the mental health disparities associated with this population by improving caregivers' interactions within their families and with child serving systems, which could in turn lower their stress and improve their quality of life. We also intend to develop a system-focused collaborative model for child serving systems to enable them to better address caregivers' needs, decrease the stigma and blame they experience, and actively involve them in the adolescents' plan of care.

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