## PURDUE UNIVERSITY GRADUATE SCHOOL

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For the degree of Master of Science	
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# PARENTS SERVED BY ASSERTIVE COMMUNITY TREATMENT: A NEEDS BASED ASSESSMENT

A Thesis

Submitted to the Faculty

of

Purdue University

by

Laura Morgan White

In Partial Fulfillment of the

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For my mother, who has always supported me.

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#### ABSTRACT

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Assertive Community Treatment (ACT) represents an effective treatment for individuals with severe mental illness. Though studies estimate that as many as half of all people with severe mental illness are parents, little is known about consumers receiving ACT services who are parents. Thus, the purpose of the present study was to 1) estimate the prevalence of parent ACT consumers, 2) identify current ACT team policies and practices for treating parent consumers, and 3) examine the perspective of parent consumers served by ACT teams. Quantitative and qualitative data were collected and analyzed via two separate studies.

In study 1, eighty-two ACT providers from 76 teams across the United States and Canada were surveyed to determine the prevalence of parent ACT consumers, ACT team policies for identifying the parental status of consumers, treatment services available for parent consumers, and provider attitudes about parent consumers. Providers estimated roughly 21.6% of ACT consumers were parents. Less than half of providers (46.3%) reported formally asking about parental status during intake and only 20.7% providers belonged to ACT teams that provide special programs/services designed for parent consumers. The majority of providers (75.6%) reported negative or mixed attitudes about parents with severe mental illness. In study 2, seventeen parents with severe mental illness being served by ACT teams were interviewed about parenting, the relationship between parenting and severe mental illness, parenting needs, and suggestions for improved treatment services for parents. All parents were able to identify at least one positive aspect of parenting and most parents (76.5%) also identified negative aspects of

parenting. Loss of custody emerged as a significant parenting problem, with the majority of parents (88.2%) experiencing loss of custody at least once. Given the difficulties of being a parent and having to manage a severe mental illness, parents expressed interest in several parent-focused treatment services, including family therapy, parenting skills, communication skills training, resources/finances for children, and social support groups with peers. When asked about overall satisfaction with ACT services, most participants with adult children (87.5%) reported having no unmet parent-related needs and high satisfaction (4.63 out of 5) with ACT services, whereas parents with young children (77.8%) reported having numerous unmet parenting needs and low satisfaction (3.78 out of 5) with ACT services. Thus, the age of participants' children was a significant factor, indicating that the ACT treatment model may not be adequately serving parents of young, dependent children. Overall, findings suggest the need for more attention and focus on parent consumers, including formal identification of consumers' parental status and improved parent-related treatment services and support.

#### STUDY 1: ASSERTIVE COMMUNITY TREATMENT PROVIDERS

#### Introduction

Following the deinstitutionalization of state hospitals beginning in the 1960s, many inpatients with severe mental illnesses were released and given the freedom to live in the community (Mowbray, Oyserman, Bybee, MacFarlane, & Rueda-Riedle, 2001). To help consumers meet the new challenges and demands related to community living, mental health providers developed community-based treatment programs, such as Supported Employment, Supported Housing, and Assertive Community Treatment (ACT) (Bond, Drake, Mueser, & Latimer, 2001; Mowbray et al., 2001). Although these community-based programs addressed needs for housing and employment, services largely failed to address larger psychosocial issues, specifically consumers' role as parents and the need for interventions addressing parent-related issues and needs. Despite evidence that a large percentage of people with mental illness have children, the mental health field has generally failed to recognize and incorporate the role of parenting in treatment and recovery (Blanch, Nicholson, & Purcell, 1994; Maybery & Reupert, 2009). The system-wide failure to address parenting in the lives of consumers with severe mental illness (SMI) may pose far-reaching and deleterious effects, given struggles faced by both parents with SMI and their children. Empirical evidence suggests parents with SMI experience more significant stressors than adults without SMI, as well as higher rates of separation, divorce, poverty, unemployment, single parent status, and risk of losing custody of their children (Mason et al., 2009; Nicholson et al., 1998). Mothers with SMI are more likely to be single mothers, experience family strife, and face victimization and sexual assault than mothers without SMI (Nicholson et al., 1998; Miller& Finnerty, 1996). Furthermore, less than half of mothers with SMI receive regular

child support or financial assistance from the other parent, with approximately two-thirds of mothers with SMI raising children below the poverty line (Mowbray et al., 2001; Ackerson 2003). Given the adversities of poverty, unemployment, and lack of social support, coupled with the difficulties of coping with SMI, parents likely struggle to function effectively in the parenting role and may need specific treatment services to address parenting needs and challenges.

Besides parents, the children of parents with SMI also face many adversities, as evidenced by strong associations between parental mental illness and deviations from normal developmental milestones, mental health, and well-being (Fudge & Robinson, 2009; Boursnell 2007). Children of parents with SMI show higher rates of inappropriate sexual behavior, obsessive-compulsive rituals, aggressive outbursts, peer problems, and delinquent behavior than children of healthy parents (Fudge, Falkov, Kowalenko, & Robinson, 2004; Stallard, Norman, Huline-Dickens, Salter, & Cribb, 2004; Maybery, Ling, Szakacs, & Reupert, 2005). The presence of parental mental illness also places children at heightened risk for developing mental illness, as well as experiencing elevated stress, high caregiver burden in having to care for mentally ill parents, and unstable parent-child relationships (Riebschleger, Tableman, Rudder, Onaga, & Whalen, 2009; Nicholson, Geller, Fisher, & Dion, 1993; Slack & Webber, 2008).

#### Prevalence of Parents with Severe Mental Illness

Despite evidence linking parental mental illness to negative outcomes, no national systematic data exists regarding the exact prevalence of parents with severe mental illness. Evidence suggests individuals with mental illness tend to marry and have children at the same rate as the general population, with roughly two-thirds of adults who meet criteria for a mental illness being parents (Miller & Finnerty, 1996; Mason, Subedi, & Davis, 2007). For the severe mental illness (SMI) population (e.g. schizophrenia, schizoaffective disorder, bipolar disorder, and major depressive disorder), an estimated one-half of all women and one-third of all men in the United States have children (Hinden, Biebel, Nicholson, Henry, & Katz-Leavy, 2006; Nicholson & Biebel, 2002). Studies in other countries have found approximately 63% of women and 26% of men with SMI in

London are parents, and roughly 59% of women and 25% of men with SMI in Australia are parents (Boursnell 2007; Diaz-Caneja & Johnson, 2004).

#### **Treatment Barriers**

Although studies suggest a high prevalence of parenthood for people with SMI, the mental health system has repeatedly overlooked parenting as a key variable in treatment services (Ackerman, 2008; Blanch, Nicholson, & Purcell, 1994; Maybery & Reupert, 2009; Slack & Webber, 2008). Numerous system-level and provider-level barriers have been identified as potential explanations for overlooking the role of parenting in treatment. To examine system-level healthcare barriers, Biebel, Nicholson, Geller, and Fisher (2006) distributed surveys to the State Mental Health Authorities (SMHA) directors in 1990 and 1999 (Biebel, Nicholson, & Geller, 1993; Biebel, Nicholson, Geller, & Fisher, 2006). Only 16 of 50 states in 1990 and 11 of 50 states in 1999 had formal policies for identifying and recording the parental status of consumers (Biebel et al., 2006). Findings from the 1999 survey also indicated only eight states provide community residential programs for parents with SMI, twelve states offer special outpatient services for parents with SMI, eleven states have formal policies to guide providers in assessing the parent functioning of consumers with SMI, and twelve states have policies for hospitalized pregnant women with SMI (Biebel et al., 2006). Thus, less than one-fourth of all states in the US require formal identification of parental status and/or provide special services for parents with SMI, indicating a large system-level failure to consider parenting as a significant factor within treatment services.

Besides system-level barriers to addressing parenting issues, numerous person-level barriers impede the consideration of parental status in treatment services. Specifically, providers have identified four key types of barriers to addressing parenting with severely mentally ill consumers: parent-related issues, child-related issues, provider-related issues, and parent-provider relationship issues (Maybery & Reupert, 2006; Blanch et al., 1994, McLennan & Ganguli, 1999; Brunette & Dean, 2002). For parent-related issues, providers report that the severity of clients' problems and mental illness, lack of understanding and knowledge about mental illness, and failure to recognize the impact

mental illness has on children make it challenging to discuss parenting with consumers (Stallard et al., 2004; Maybery & Reupert, 2006). Further, parents with SMI sometimes remain silent about parenting issues, out of fear of being stigmatized or unfairly deemed an unfit parent (Fox, 2009; Kundra & Alexander, 2009; Diaz-Caneja & Johnson, 2004; Wilson & Crowe, 2008).

Regarding child-related barriers, parents may choose to keep their children uninvolved in treatment because treatment might be too confusing, overwhelming, or burdensome for their children (Stallard et al., 2008). Children sometimes refuse to participate in family interventions, whereas other children are unable to take part in treatment due to placement in a foster home or other residence (Stallard et al., 2008; Maybery & Reupert, 2006). These issues may cause parents to avoid discussions of parental status or decline parenting services; effectively denying providers the opportunity to address the issue of parenting with consumers (Nicholson et al., 2007; Hinden et al., 2006).

Provider-related issues, such as lack of time, resources, and general knowledge about parenting needs, also impede the consideration of the parental status of consumers. According to providers, managing a large caseload of clients with SMI requires ample attention and energy, with little time or resources left to consider the well-being of children of consumers (Maybery & Reupert, 2009; Stallard et al., 2008; Fudge et al., 2004). Though all providers acknowledge the importance of the parenting role, providers outside the field of social work report a lack of knowledge, skills, and confidence in working with children, parents, and families (Maybery & Reupert, 2009; Maybery & Reupert, 2006; Stallard et al., 2008). Social workers are trained in a philosophy that incorporates the whole family, and studies indicate social workers spend significantly more time than other providers discussing parenting issues with consumers, spending time with consumers' family members, and reporting that parenting services are part of their job (Maybery & Reupert, 2006; Slack & Webber, 2008; Maybery & Reupert, 2009). Not surprisingly, multidisciplinary teams with social workers have been found to have greater awareness of the rights and needs of parent consumers (Slack & Webber, 2008; Ackerson, 2003).

Besides training deficits, provider attitudes also contribute to problems with addressing parental status of consumers. Mental health providers sometimes fail to ask about parental status because they inaccurately assume consumers are not parents (Maybery & Reupert, 2009; Nicholson & Biebel, 2002). Providers sometimes hold negative attitudes towards parents with SMI, believing these individuals lack the skills or desire to raise children (Hinshaw & Cicchetti, 2000; Brunette & Dean, 2002; Nicholson & Biebel, 2002; Eack & Newhill, 2008). Unfortunately, parents with SMI notice these negative attitudes among providers, reporting that providers' demeaning attitudes and low expectations make it difficult to talk about parental issues (Hinshaw, 2005). Thus, the negative attitudes held by providers may cause providers to avoid discussing parental status or offering parent-focused treatment services, while simultaneously encouraging consumers to remain silent about parenting and avoid seeking parent-related treatment services (Nicholson & Biebel, 2002; Nicholson et al., 1998).

The final barrier to adequate treatment for parents with SMI involves provider fear that discussions of parenting issues might offend consumers, insinuate poor parenting, and disrupt the therapeutic alliance (Maybery & Reupert, 2006). Specifically, providers fear consumers might become defensive and unwilling to share their problems, rendering providers unable to help consumers. Thus, in an effort to keep a good therapeutic alliance, providers may intentionally avoid discussing parenting problems, despite consumer interest in addressing these issues (Brunette & Dean, 2002; Diaz-Caneja & Johnson, 2004). While providers worry about the therapeutic alliance, interviews of parents with SMI indicate great interest in incorporating parenting into psychiatric services. Specifically, parents with SMI want more emphasis on parenting, including parenting skills training, therapy sessions with children, open communication with providers, and peer support groups with other parents (Boursnell, 2007; Diaz-Caneja & Johnson, 2004; Wilson & Crowe, 2008).

#### Statement of the Problem

Though research has examined general system-level and person-level barriers to the identification and consideration of consumers' parental status in treatment services, there is little data on potential barriers associated with specific interventions for people with SMI (Fudge & Robinson, 2009; Hinden et al., 2006; Nicholson et al., 2007). Since studies assessing the policies and services for parents with SMI have tended to sample broadly, differences in outcomes tend to be conflated with the different treatment interventions included in the analyses. For example, Nicholson and colleagues (2007) found evidence-based practices (EBPs) for the treatment of SMI do not promote positive outcomes for parents and their children (Nicholson, Hinden, Biebel, Henry, & Katz-Leavy, 2007). While these findings suggest potential weaknesses in current EBPs, valuable conclusions about specific interventions cannot be drawn since interventions may differ in helpfulness and openness to assisting parents with SMI. Thus, a careful examination of one specific evidence-based intervention for SMI is clearly warranted.

The current study will explore the policies, practices, and services available for parent consumers served by the EBP known as Assertive Community Treatment (ACT). The strong empirical support and the large number of consumers served by ACT make this intervention an appropriate choice for analysis (Bond et al., 2001; Gerwurtz et al., 2004). ACT is a community-based intervention for individuals with severe mental illness who have a history of intensive use of mental health services and difficulties living in the community (Bond et al., 2001). Multidisciplinary teams of providers work together to provide comprehensive, intensive, community-based, and long-term treatment for a caseload of clients. ACT providers offer assistance with medication, housing, finances, employment, and other community living issues, as well as twenty-four hour daily availability for crisis management (Bond et al., 2001). Research indicates ACT is effective in reducing consumer hospitalizations, relapses, and symptoms, as well as increasing community functioning and overall quality of life (Bond et al., 2001; McGrew, Bond, Dietzen, & McKasson, 1995).

While the primary objective of ACT is to promote and maintain adaptive functioning of consumers in the community, the ACT treatment model does not emphasize the role of parenting in the design and implementation of treatment services. Currently, there is very limited data on the prevalence of parent consumers currently being served by ACT. One study found approximately 38% of ACT consumers is parents,

though the estimate is based on a small sample of 181 clients from four ACT teams in Ontario, Canada (Gerwurtz et al., 2004). No study to date has broadly and systematically examined the prevalence of parents served by ACT teams, or the number of ACT teams that routinely identifies the parental status of consumers. Furthermore, little research exists regarding the policies and practices of ACT teams in identifying and incorporating parenting needs and services into treatment plans.

Accordingly, the study attempted to estimate the prevalence of parent consumers receiving ACT services and examined program-level policies and practices of ACT providers in identifying and treating parent consumers. The study also examined provider attitudes about parenting and mental illness, including how these issues impact one another, barriers to discussing parenting with consumers, and potential benefits of addressing parenting with consumers. Possible relationships between team or provider characteristics and policies for treating parent consumers were specifically examined. Given evidence that social workers are better trained and equipped to address parenting issues than other academic disciplines, social workers were hypothesized to discuss parenting issues more often than other providers and teams with social work leaders were hypothesized to show higher levels of assistance with parenting needs than other teams (Ackerson, 2003; Maybery & Reupert, 2009; Slack & Webber, 2008).

#### **Summary of Research Questions**

The main research questions for the study were as follows:

- 1. How many ACT consumers are parents?
- 2. What are the policies of ACT teams for identifying parental status of consumers?
- 3. What parent-related issues do ACT providers discuss with consumers? What parent-related needs do ACT providers offer assistance with for consumers?
- 4. Does the provider's role on the team relate to the likelihood of discussing parentrelated issues?
- 5. What are the general attitudes of ACT providers regarding parenting and mental illness?

#### <u>Methodology</u>

#### **Participants**

The target population for the study was ACT providers currently serving consumers with severe mental illness (e.g. schizophrenia, schizoaffective disorder, bipolar disorder, or major depressive disorder). Inclusion criteria required participants to be active members of an Assertive Community Treatment team and willing to complete a survey about team policies and practices. Serving consumers with children was not a requirement for participation in the study.

#### Recruitment

Potential participants initially were recruited during the 26th Annual ACT Conference, hosted by the Assertive Community Treatment Association Inc, on June 17-20, 2010, in Chicago, IL. ACT teams from the United States and Canada attended the three-day conference. During the conference, the primary researcher sat at a table with information about the study. The researcher either asked conference attendees who passed by the table or personally approached attendees to take part in the study. To aid in recruitment, flyers and large signs were posted throughout the lobby area, which listed the study purpose, procedure, participant rights, and chance to win a \$25 gift card for interest in the study. Because attendees of the ACT Conference represented only a subsample of the target population, additional ACT providers identified through ACT listservs were contacted via email in August 2010 to participate in the study. Potential participants received recruitment emails detailing the nature and purpose of the study, including the change to win a \$25 monetary gift card.

Most participants (91.5%) were attendees of the ACT Conference and completed the survey at the main study table or at a neighboring table, though some participants took the survey and completed it at a later time and different location. Participants contacted via email completed the surveys individually and privately at a setting of their choice.

#### Measure

A 21-item survey, labeled ACT Team Survey, was created specifically for the study (See Appendix A). Two items were adapted from the 1990 State Mental Health Authority (SMHA) survey of programs and policies for mothers with SMI (Biebel, Geller, Fisher, and Dion, 1990): 1) Are all adult clients formally identified as parents by the SMHA and 2) Does the SMHA have community/rehabilitation, employment/vocational, clubhouse, day treatment, or other outpatient services/programs for adult clients who are parents (Biebel et al., 2006). These questions were modified to reference ACT teams rather than SMHA programs. The remaining 19 items assessed ACT teams' policies, attitudes, and treatment services for parent consumers. Three ACT experts reviewed survey drafts for clarity and content coverage through several rounds of revisions to produce the final ACT Team Survey.

The 21-items included seven fill-in-the-blank questions about general consumer demographic and ACT team characteristics, such as the number of consumers being served by a team or the state in which the team serves consumers, and six close-ended questions with specific answer options or checkboxes assessing provider and team practices, such as methods for identifying parental status of consumers and frequency in which parent-related issues are discussed with consumers. An "other" option was provided to allow participants to report answers not captured by the answer options. The measure also included eight open-ended qualitative questions designed to explore team policies and provider attitudes, including provider attitudes about parenting and SMI, comfort discussing parenting with consumers, and barriers to treatment. Example questions included, "Do you feel comfortable discussing parenting issues with consumers? Why or why not?" "What do you think are the biggest challenges or barriers to addressing parenting issues with consumers?" "How do you think parenting affects mental health and illness?" and "How do you think mental illness affects people's ability to parent?" (See Appendix A).

#### Procedure

Participants who took part in the study at the ACT Conference were informed of the nature and purpose of the study and verbal consent was obtained. Participants were then invited to write their name and address on an index card to enter a raffle for a \$25 monetary gift card and received a copy of the ACT Team Survey. Participants were encouraged to voice questions about the survey. Upon returning the completed surveys to the researcher at the main study table participants were provided contact information for follow-up questions.

Participants contacted via email received a recruitment email detailing the purpose of the study, risks, participant rights, and chance to win a \$25 monetary card. An electronic copy of the survey was attached to the email. Participants were instructed to individually complete the survey in private and email, mail, or fax it to the primary researcher. Participants who returned the survey were sent a thank you email for taking part in the study, as well as the researcher's contact information. One ACT conference participant and one listsery participant were selected at random to receive gift cards, which were mailed to the winners. Study procedures were reviewed and approved by the Institutional Review Board at Indiana University-Purdue University Indianapolis, in Indiana

#### Quantitative Data Analysis

Data were examined for outliers, missing values and variable distributions. Responses listed as percentages (e.g. percentage of the caseload) were converted into whole numbers. If a range of values was provided, the midpoint was used. Persons with variables with missing values or undecipherable responses were eliminated from analyses on a case-by-case basis, using pairwise deletion. Variable distributions with skewness < 2 and kurtosis < 5 were considered normal. Four variables exceeded kurtosis of 5 (caseload, client-team ratio, Hispanic prevalence, and other race prevalence) and were log-transformed before being analyzed. Variables available for data analysis included five team variables (caseload, team size, caseload-size ratio, urban location, and team leader profession), five caseload variables (female prevalence, African American prevalence,

Caucasian prevalence, Hispanic prevalence, and other race prevalence), five team role variables (psychiatrist/nurse practitioner, psychologist/therapist, social worker, peer consumer, and other), and two parent-related prevalence variables (parent prevalence, mother prevalence).

Focused statistical analyses were conducted for each research question, using variables identified a priori (identified below in results). Chi-square was used to test associations with nominal variables (e.g. role on team, urban, etc.), and t-tests were used for continuous variables (parent prevalence, race/ethnicity prevalence, etc.). Ratings for eight parenting issues (identified below in results) were collapsed into an eight-item Parenting Issues Scale. Attempts to group the eight issues into several broad subcategories were not successful. Internal consistency ( $\alpha = .875$ ) was highest when all eight items were treated as a single dimension (e.g. Parenting Issues Scale), so that removal of any of the eight issues reduced overall consistency. Ratings for ten parenting needs (identified below in results) were also collapsed into a ten-item Parenting Needs Scale. Again, attempts to group the issues into broad sub-categories were not successful and internal consistency ( $\alpha = .804$ ) was highest when all ten needs were treated as a single dimension (e.g. Parenting Needs Scale).

#### Qualitative Data Analysis

The primary author and a research assistant, together with consulting help from an expert on qualitative data analysis, examined participant responses to the open-ended questions. All responses were transcribed and entered verbatim into SPSS. Missing or unreadable responses were excluded from the analysis. Emergent categories were identified using a content analysis approach. Researchers read through responses and noted common types of responses. Preliminary themes were identified and tested on fresh sets of responses. Themes were modified using an iterative approach through three rounds of revisions, in which themes were eliminated, combined, or expanded, to best capture the data. The final set of themes was included in a codebook for data analysis (Appendix B). The number of emergent categories identified ranged from seven to eleven themes per question. A total of 54 separate themes were identified for eight qualitative

questions (See Table 5). Each theme was treated as a separate variable for data entry, with responses coded as 0 = theme not evident and 1 = theme present. Depending on complexity, a participant's response could be coded as satisfying more than one theme.

Responses for six of the eight questions were coded using a single step procedure and two questions were coded using a two-step procedure. For the one-step coding process, answers were coded according to the themes identified in the response. Each response could be coded as including several themes. That is, participants were given credit for multiple-part answers falling under several response themes. The frequencies of responses within each separate theme are displayed in Table 5. For the two questions using the two-step coding process, participant answers were coded first according to the degree to which the response was affirmative/positive, not affirmative/negative, or both positive and negative. Answers were then coded according to response themes, as previously discussed in the one-step coding process. For example, participants were asked how parenting affects mental health and illness. One participant reported, "can cause increased stress, frustration, anxiety, and lower self-esteem." Based on the two-step coding process, this response would first be coded as negative, because the response lists negative consequences of parenting on mental illness. The answer was then coded according to response themes, specifically under the "increases symptoms" theme and the "source of stress" theme (See Appendix B).

To ensure coding reliability, two raters independently coded all qualitative responses. Raters later met to resolve discrepancies and reach a consensus. Overall, interrater reliability between the two raters as measured using the intraclass correlation was acceptable for the vast majority of the themes coded. Forty-nine of the fifty-four (90.7%) themes had acceptable reliability, with values of .60 or higher (ICCs ranged from .62 to 1.00). The remaining five themes with the lowest overall reliabilities included three "Other" themes (ICCs ranged from .26 to .42), the "Advantages of Discussing Parenting: Therapeutic Alliance/Support Consumers" theme (ICC = .46), and the "Mental Illness Impacts Parenting: Motivation in Treatment and Recovery" theme (ICC = .38) (See Table 5).

#### Results

#### **ACT Provider Sample**

Eighty-two ACT providers from 76 different ACT teams participated in the study. Providers served in a variety of roles, with less than half the sample (39%) identified as team leaders (See Table 1). Altogether, providers served 5,766 consumers across the 76 teams, with an average team caseload size of 76.5 consumers and caseload to team member ratio of 7.8:1. Slightly more consumers were male (58.7%) and Caucasian (54.9%) (See Table 2). ACT team caseload race/ethnicity was distributed bi-modally, with 6 teams serving primarily Caucasian consumers (80% or higher) and 22 teams serving primarily racial/ethnic minority consumers (80% or higher). Teams reported serving primarily urban areas (62.2%) or a mixture of urban and rural areas (22%), and were located in 27 different states and Canada (See Table 1).

#### Prevalence of Parent Consumers

A primary study aim was to determine the parent prevalence among ACT consumers. As displayed in Table 3, the percentage of ACT consumers (N = 5766) across the 76 teams who were parents was 21.6% (N = 1247; 95% confidence interval (CI): 20.6% - 22.7%). Regarding parental gender, 18.1% (N = 1037; CI: 17.1% - 19.2%) of all consumers were identified as mothers and 3.6% (N = 210; CI: 3.2% - 4.2%) of all consumers were identified as fathers. Overall, 83% (1037 of 1247) of the identified parents were mothers. Parent prevalence estimates varied greatly across teams, ranging from 0% to 90% of the total caseload. Providers also reported some uncertainty regarding parent status, noting that they were unsure of the parental status of 6.4% (N = 369; CI: 5.8% - 7.1%) of consumers. Providers also were unsure of the plans of 14.2% (N = 821; CI: 13.3% - 15.1%) of consumers to have children, though estimates greatly varied from 0% to 100% across team. Finally, providers reported that 12.1% (N = 696; CI: 11.2% - 12.9%) of consumers wanted more children, with estimates again ranging from 0% to 100% across teams (See Table 3).

#### Assessment of Parental Status

Two question formats were used to assess methods for assessing parental status. Answers varied depending on the question format used. In response to an open ended question about determining parental status of consumers, providers reported using an intake form or intake interview (46.3%), assessments (29.3%, e.g. behavioral health assessment, biopsychosocial assessment), consumer self-report (24.4%), charts or records (19.5%, e.g. hospital records, past treatment charts), information derived from referral sources (14.6%, e.g. child protection, the court), pregnant or have children present (4.9%), and other methods (8.5%) (See Table 4). For providers who regularly identify parental status during intake, they reported using a variety of questions, such as directly asking consumers, "Do you have children" (25.6%), "How many children do you have?" (8.5%), "How is the relationship?" (6.1%), and "Do you have custody of your children?" (2.4%). In response to a close-ended question in which providers were prompted to select which methods they used from a set of pre-selected options, the majority of participants selected "formally ask during intake/initial assessment" (93.9%) as the primary means to identify parental status (See Table 4).

To explore factors associated with assessing parental status at intake, bivariate relationships were examined between teams reportedly using formal assessment with intake form/interview and the following categories of predictors: team characteristics (2 variables, e.g. caseload-team size ratio and team leader profession), caseload characteristics (3 variables, e.g. Caucasian prevalence, female prevalence, and parent prevalence), and informant's team role (3 variables, e.g. psychologist/therapist, social worker, and peer consumer). Out of the eight associations examined, the only significant finding was an inverse relationship between peer consumer and assessment of parental status at intake/initial assessment ( $\chi^2(1) = 6.90, .009$ ). That is, peer consumers were significantly less likely than other team members to ask consumers about parental status during the initial intake/assessment.

#### Parent-Related Issues

ACT providers were asked to report the frequency, ranging from never (1) to always (4), with which they discuss the following eight issues with consumers: desire to have children, desire for a committed relationship, desire for a sexual relationship, safe sexual practices, family planning methods, parenting problems, parenting responsibilities, and custody issues). Results indicate providers tend to discuss parenting issues occasionally (2) or often (3) with consumers, with the most time spent discussing safe sexual practices (M = 2.8, SD = .83). Over half of providers (58.6%) reported discussing safe sexual practices often or always with consumers, whereas few providers (17.1%) reported discussing the desire to have children often or always (M = 2.1, SD = .60). Other needs discussed occasionally to often with consumers included parenting problems (M = 2.6, SD = .77), parenting responsibilities (M = 2.5, SD = .73), desire for a committed relationship (M = 2.46, SD = .64), family planning methods (M = 2.4, SD = .83), custody issues (M = 2.4, SD = .75), and desire for a sexual relationship (M = 2.3, SD = .64).

To explore factors associated with addressing parent-related issues, average scores for frequency discussing all eight issues were calculated (M = 2.44, SD = .54). As discussed in data analysis, attempts to collapse the eight parent-related issues into several sub-categories were not successful, so all eight items were treated as a single dimension (e.g. Parenting Issues Scale,  $\alpha$  = .875). The mean scores for the Parenting Issues Scale were calculated for each participant and bivariate relationships were examined between scale scores and the following predictors: team characteristics (3 variables, e.g. caseload-team size ratio, team leader profession, and location (urban/rural), caseload characteristics (3 variables, e.g. Caucasian, female, and parent prevalence), and role on ACT team (2 variables, e.g. social worker and psychologist/ psychiatrist).

No significant relationships emerged between the frequency of discussing parenting issues and participant role on team, location, race/ethnicity of consumers, gender of consumers, or prevalence of parent consumers. Team leader profession was nearly significantly associated with the Parenting Issues Scale ( $\chi^2(1) = .226$ , p = .06). Sub-analyses of specific parenting issues showed that teams with social work team leaders reported spending more time discussing desire to have children (r = .359, p

= .004), which was confirmed by a t-test comparing teams with social work leaders and leaders of other professions (t(76) = -2.665, p = .01). Caseload-team size ratio was also nearly significantly associated with the Parenting Issues Scale (r = -.224, p = .073). When examined at the item level, teams with more staff per consumer spent more time discussing desire for a committed relationship (r = -.326, p = .008), family planning methods (r = -.337, p = .006), and safe sexual practices (r = -326, p = .008).

#### Parent-Related Needs

In addition to parent-related issues, the types of parent-related assistance provided by ACT teams were examined. Teams reported helping consumers with the following needs: court appointments/custody hearings (63.4% of ACT teams), communication/interaction with children (52.4%), food for children (43.9%), clothing/personal items (40.2%), medical needs (28%), housing of children (28%), transportation for children (24.4%), discipline (22%), daycare/babysitting (18.3%), and helping consumers assist their children with schoolwork (7.3%). As discussed in data analysis, attempts to collapse the ten parenting needs into several sub-categories were not successful, thus all ten items were treated as a single dimension (e.g. Parenting Needs Scale,  $\alpha = .804$ ). The mean scores for the Parenting Needs Scale were calculated for each participant (M = .33, SD = .27) and bivariate relationships were conducted between scale scores and the following categories of predictors: team characteristics (2 variables, e.g. caseload-size ratio and team leader profession), caseload characteristics (3 variables, e.g. Caucasian, female, and parent prevalence), and team role (2 variables, e.g. social worker and psychologist/psychiatrist).

There were no significant relationships between the Parenting Needs Scale and team leader profession, role on team, or caseload-size ratio. Significant relationships did emerge for female and parent prevalence, with teams reporting caseloads with a greater number of females (r = .306, p = .015) and greater number of parents (r = .347, p = .003) being significantly more likely to help with parent-related needs. Sub-analyses of specific needs revealed significant positive relationships between higher prevalence of female consumers and assistance with medical needs (r = .255, p = .044), court/custody (r = .282,

p = .025), and clothing items (r = .390, p = .002). Significant relationships also emerged between teams reporting higher caseloads of parents and assistance with daycare needs (r = .372, p = .002) and housing (r = .245, p = .034). Finally, when parenting prevalence was restricted to mothers, teams reporting a higher prevalence of mothers were also more likely to report helping with daycare (r = .426, p < .001), court/custody (r = .364, p = .002), and housing (r = .330. p = .005). Thus, results indicate teams serving a higher percentage of parents, particularly female parents, tend to offer more assistance with certain parenting needs (e.g. custody, daycare, and housing).

Significant relationships were found between the Parenting Needs Scale and caseload prevalence of Caucasians consumers (r = -.310, p = .007). Bivariate correlations examining specific needs showed an inverse relationship for teams reported lower prevalence of Caucasian consumers and higher assistance with custody needs (r = -.322, p = .005). Due to significant findings for caseload ethnicity, additional sub-analyses were conducted examining other ethnicities (e.g. African American, Hispanic and other race prevalence). A significant positive relationship emerged between the Parenting Needs Scale and teams reporting caseloads with a higher prevalence of African Americans (r = .325, p = .004), with sub-analyses of specific needs indicating positive relationships between the prevalence of African American consumers and team assistance with custody needs (r = .278, p = .015), helping with schoolwork (r = .229, p = .047), transportation (r = .241, p = .036), and food (r = .271, p = .018). These findings suggest teams with higher percentages of African American consumers are more likely to assist with needs, such as custody, transportation, school, and food needs. It should be noted that only 6 teams (7.3%) offer assistance with helping children with schoolwork, so findings about help with schoolwork may reflect a small subset of team and may not be applicable to most ACT teams.

#### **Provider Attitudes**

As shown in Table 5, the majority of providers (91.5%) indicated feeling comfortable discussing parenting issues. The most frequently reported reasons for feeling comfortable included sufficient provider training (31.7%, e.g. "part of job," have skills as

provider), part of treatment and recovery (24.4%), and parenting is crucial part of life (22%, e.g. part of client's system, important life issues). With respect to barriers to addressing parenting issues and needs, the most frequently reported issues were parenting is sensitive issue/consumer is defensive (25.6%), custody issues (19.5%, e.g. "consumers don't have custody" or "clients feeling threatened that their children might get taken away"), staff barriers (15.9%, e.g. not part of job, no training), consumers' poor parenting skills/bad behaviors (15.9%, e.g. "not able to take care of them," "parenting skill building is needed"), consumers' lack of insight regarding parenting (14.6%, "unrealistic beliefs," "don't understand the level of responsibility parenting entails"), and severe mental illness and/or substance abuse (13.4%) (See Table 5). In contrast, participants identified several advantages to addressing parenting with consumers, such as improves consumers' efficacy and self-esteem (35.4%), enhances parenting skills (32.9%), strengthens therapeutic alliances and/or supports consumers (29.3%), and improves relationship with children/expands social support (22%) (See Table 5).

When asked how parenting affects mental health, participants provided mostly negative responses (53.7%, e.g. adds stress, drains finances, etc.) or mixed responses (29.3%, e.g. children bring much joy and socialization, but are also very stressful). Commonly held beliefs about how parenting affects mental health included source of stress/additional burden (48.8%), increases symptoms/exacerbates SMI (39%), positive impact, but no explanation (14.6%), source of motivation/aids treatment and recovery (12.2%), causes problems for children (8.5%), increases responsibilities of consumers (7.3%), stigma (6.1%), reduces resources/finances (3.7%), and other (15.9%). When asked how mental health affects consumers' ability to parent, participants also provided generally negative responses (56.5%, e.g. cannot follow through with parenting responsibilities) or mixed responses (30.5%, e.g. depends on the consumers' ability to manage mental illness) when asked how mental health affects ability to parent. Commonly reported beliefs included reduces parenting abilities/skills deficit" (53.7%), "depends on consumer" (26.8%), depends on support network/participation in therapy (11%), causes problems for children (11%), positive impact (11%, e.g. makes person a better parent), source of stress/additional challenge (8.5%), reduces resources/finances

(6.1%), stigma (4.9%), source of motivation/aids recovery (2.4%), and other (13.4%) (See Table 5).

#### Discussion

#### Prevalence of Parent Consumers of ACT

The study was generally successful at achieving its goals of identifying the prevalence of parent consumers, methods for the identification of parent consumers, types of supports for parent consumers on ACT teams, and general provider attitudes about parents with SMI. Based on a diverse sample of 82 ACT providers from 76 teams in the United States and Canada currently serving 5,766 consumers, approximately 21.6% of ACT consumers were identified as parents, with the majority (at least 83%) of parents being mothers. Overall, approximately 18.1% of ACT consumers were identified as mothers and 3.6% of consumers were identified as fathers. With the exception of one small study involving four ACT teams in Canada, the study represents the first large-scale attempt to estimate the parent prevalence of ACT consumers.

Contrary to expectations, study estimates were significantly lower than other studies of prevalence rates for parents with mental illness or dual psychiatric and substance use disorders, which tend to report prevalence rates comparable to the general non-mentally ill population, with at least half of all individuals being parents (Nicholson & Biebel, 2002). Moreover, the study found much lower estimates for parent prevalence than both the single prior estimate from four ACT teams in Canada (38% of ACT consumers, with 22% of caseload being mothers and 16% of caseload being fathers) and estimates of the prevalence of parents with severe mental illness served in public mental health services in the United States (50% of women and 33% of men), in Europe (63% of women and 26% of men), and in Australia (59% of women and 25% of men) (Gewurtz et al., 2004; Hinden, et al., 2006; Nicholson & Biebel, 2002; Boursnell, 2007; Diaz-Caneja & Johnson, 2004).

Several explanations, either singly or together, may account for the smaller parent prevalence rate found in the current study. First, ACT consumers may represent a unique portion of the SMI population, who experience more severe mental health symptoms and/or other life challenges, reducing the likelihood of being parents. However, such an explanation cannot explain differences with the prevalence estimates from the

Canadian study of parent prevalence (Gewurtz et al., 2004), which were based on ACT consumers. Instead, it is possible that providers in the current study may have underestimated the true prevalence of parents, due to failure to assess it, being unaware of the parental status of consumers, or not having access to relevant client information (e.g. charts). Previous research has shown that roughly two-thirds of mental health providers make erroneous assumptions about consumers' priorities regarding treatment services and overestimate their understanding of consumer needs (Fischer, Shumway, & Owen, 2002). It should be noted that the Canadian ACT study (Gewurtz et al., 2004) directly surveyed ACT consumers, who can be assumed to be more accurate sources of information regarding parental status. Thus, study findings may indicate that ACT providers are generally unaware of parent consumers, resulting in marked underestimates of the parental prevalence of ACT consumers.

Future studies should use a variety of methods to verify parental status (e.g. directly asking clients, access to client records) to determine prevalence rates, rather than making calculations based on ACT provider estimates. However, most providers indicated strong confidence in their responses, providing evidence that either the relatively low parent prevalence found may be generally accurate or providers are unaware that they provided inaccurate information. Finally, definitions of what is meant by SMI vary markedly across studies making exact comparisons difficult. Estimates in the literature often include individuals with a mental illness, but not necessarily a severe mental illness, and thus may overestimate the prevalence of parents with "true" SMI (e.g. diagnosis of schizophrenia, schizoaffective disorder, bipolar disorder, or major depressive disorder plus impaired functioning).

#### Assessment of Parental Status

The study examined the methods ACT teams use to identify parent consumers. Previous research has found that less than one-fourth of all states require formal identification of parental status of consumers or provide programs specifically tailored for parents with SMI (Biebel, Nicholson, Geller, & Fisher, 2006). In addition, an estimated 55-80% of psychiatric clinical records do not report the custody status or

whereabouts of consumers' children (Mowbray et al., 2001). Contrary to these findings, the majority of ACT providers in the study reported regularly using a variety of formal and informal methods for identifying parental status of consumers. The most common forms of identifying parents included formal identification during intake (46.3%), during assessments (29.3%), through consumer self-report (24.4%), or examination of consumer charts/records (19.5%). When asked to check whether their ACT team identifies parental status via a list of options, almost all providers (93.9%) indicated determining parental status during formal intake/interview. However, since findings suggest providers underestimated the number of parent consumers, it is possible that providers may not be assessing parental status consistently or parent consumers may not be reliably informing them of their parental status. Given that only about one-fifth of providers reportedly belong to teams that offer specific services for parent consumers, like family therapy or parenting classes, parent consumers may not see any benefits to revealing parental status.

Overall, findings about team policies and practices should be interpreted with caution, since responses may be biased. In an effort to appear competent, providers may have reported utilizing methods that are actually used infrequently by themselves and/or other team members. It should also be noted that the study did not specifically assess whether the provider or the team personally used an identification method (e.g. formally asking during intake or informal discussing parental status during therapy sessions), but only whether the team in general used an identification method. The study also did not collect data regarding the percentage of consumers that a provider utilizes the identification method(s) with, or the frequency with which different methods of identification are implemented by providers and ACT teams. Conclusions are therefore limited to team self-report and should be interpreted with caution.

#### Impact of Team Characteristics on Services

Despite prior research indicating (Slack & Webber, 2008) that provider training and discipline impacts how providers treat and serve parent consumers, the study failed to find strong evidence supporting any relationship between the participant's discipline and reports of treatment provision. Provider role on team and team leader profession showed

no significant effect on discussion of parent-related issues or assistance with parent-related needs, except for one finding that teams with social work leaders were more likely to take time to talk with consumers about children than teams with non-social work leaders. The finding is consistent with previous studies, which have shown that multidisciplinary teams consisting of social workers tend to have greater awareness of the rights and needs of clients regarding family issues than teams without social workers (Slack & Webber, 2008).

Several explanations may account for the absence of strong findings between provider role/discipline and treatment services. First, the study was underpowered due to the small number of providers in each role (e.g. only 10 psychologists, 15 case managers, etc.), thereby reducing the likelihood of finding significant effects. Second, survey response options may not have been sensitive enough to capture true differences across providers. Specifically, providers rated the frequency with which they discuss parenting issues on a 4-point scale and reported whether or not they assist with different parenting needs. Such crude estimates of treatment provision may not have accurately captured significant relationships between provider role/discipline and treatment services. Finally, because the treatment model for ACT does not traditionally emphasize parenting, providers on ACT teams, regardless of specific role, may not regularly consider or address the role of parenting with consumers (Bond et al., 2001).

Although provider role was not associated with team-reported provision of treatment services, other characteristics of ACT teams were significantly associated with services for parent consumers. Specifically, teams with more staff per consumer, as measured by the caseload to team member ratio, provided more intensive services to parent consumers, by devoting more time to discussing issues such as being in a committed relationship, safe sexual practices, family and family planning methods. Such findings seem plausible for two reasons. First, compared to teams with larger client to team member ratios, ACT teams with smaller ratios likely have more time and/or resources to handle complex problems and needs of consumers. Second, teams with more members likely have more providers available to help parent consumers, as well as

heightened diversity among staff positions and expertise, which allows larger teams to address various areas affecting consumers, including parent-related issues.

#### Impact of Caseload Characteristics on Services

Interestingly, teams with higher percentages of racial/ethnic minority consumers were found to spend significantly more time assisting with court/custody problems, food, transportation, and school needs. Evidence suggesting that ethnic minorities tend to become parents at a younger age and have more children than Caucasian individuals may partially explain these findings, since having more children would increase the need for assistance with parenting needs (Miller & Finnerty, 1996; Gerwurtz, et al., 1999). Furthermore, research has shown families involved with Child Welfare Services Agencies are disproportionately African American and that parents with disabilities, such as having a mental illness, often experience discrimination during termination of parental rights proceedings (Phillips, Burns, Wagner, & Barth, 2004; Kundra & Alexander, 2009). In fact, federal courts have ruled against parents with mental illness in many termination of parental rights hearings, due to stringent legal standards that are difficult for parents with SMI to meet (Kundra & Alexander, 2009). Therefore, ethnic minority parents likely face heighted discrimination in court, due to both race/ethnicity and having a mental illness, resulting in higher risk of custody loss and need for assistance with court/custody issues, as found in this study. Unfortunately, the literature examining the relationship between race/ethnicity of people with SMI and custody issues is not yet well established, so future studies are needed to better assess the relationship between race/ethnicity of consumers with SMI and assistance with custody needs.

Alternative explanations for study findings may be that teams serving higher caseload of African Americans and providing more parent-related services also tend to have caseloads of consumers of low socioeconomic status (SES) and/or living in urban areas, thereby driving the need for higher provision of services. Since data on the SES of consumers was not collected, conclusions cannot be made about the impact of SES on treatment services. However, no significant findings emerged for type of city, with teams serving in urban, rural, and suburban settings all showing similar rates of treatment

services. Thus, it seems likely that different parenting rates (e.g. age at first child and number of children) and treatment by the legal system across different ethnicities account for the findings.

## Provider Attitudes and Experiences

Finally, the study examined ACT providers' attitudes regarding parenting and mental illness. Despite considerable research showing that the majority of parents with SMI view their role positively, as a genuine source of pride and motivation (Oyserman et al., 2004), the majority of ACT providers endorsed predominantly negative opinions. In fact, at least 75% of providers gave negative or mixed responses to questions about how parenting affects mental illness and how mental illness affects parenting. Specifically, providers indicated that being a parent likely causes additional stress, exacerbates symptoms of SMI, increases consumers' burdens and responsibilities, and drains consumers' finances and available resources. These providers also reported that having a severe mental illness may negatively impact ability to parent by diminishing parenting skills, causing problems for children, increasing levels of stress, and generating stigma or guilt about being a parent with a mental illness.

Similar to current findings, previous research with mental health providers has also found negative attitudes about parent consumers, despite positive attitudes endorsed by consumers who value being a parent (Ackerson, 2003; Hinshaw & Cicchetti, 2000). Unfortunately, there appears to be a large discrepancy between provider attitudes and consumer attitudes about being a parent with mental illness. Although some providers stressed the positive aspects of being a parent with a SMI, such as deriving satisfaction and self-efficacy in being a good parent, many providers failed to consider the positive impact that parenting may play in consumers' lives. By assuming that parenting is too overwhelming and burdensome for consumers with SMI, providers may not offer the services parent consumers really want and need, thereby failing to provide the intensive services required of the ACT treatment model. Changing providers' negative attitudes and beliefs about parent consumers with SMI would likely result in better communication

and stronger therapeutic alliances between providers and consumers, as well as enhanced outcomes for ACT parents with severe mental illness.

## Study 1 Limitations

Although the study was able to answer several important research questions, several limitations must be noted. First, with limited funding, time, and resources available for the study, opportunity sampling was used rather than a more rigorous, random sampling approach. Thus, all ACT providers in the United States and Canada did not have an equal chance of being included in the study. A convenience sample was used, consisting of participants who completed the study at the ACTA Conference in Chicago, IL, or via an online survey. Efforts to recruit participants online were disappointing, with an extremely low response rate. Despite problems with recruitment and non-random sampling, 82 participants from 76 different ACT teams in both rural and urban areas of 27 states and 4 provinces in Canada were included in the study. The sample was therefore relatively diverse and likely representative of most ACT teams in the United States and possibly Canada.

Second, the method of recruitment for the study, which included directly asking people to participate, may have introduced self-selection bias because participants interested in parenting and mental illness were probably more likely to agree to participate than people not interested in the research area. Third, since the survey was specifically created for the study and not pilot tested, content validity of the measure cannot be assumed. Firm conclusions regarding whether the survey items were relevant, clear, and understood by all participants cannot be drawn. Fourth, the study is limited to self-reported information, with no mechanism to ensure participants responded accurately and truthfully to survey questions. While it seems unlikely ACT providers intentionally reported inaccurate survey responses, providers may have guessed or estimated on survey items seeking prevalence data. Participants may have also given inaccurate and/or biased answers regarding policies and services offered to consumers, as well as attitudes about parent consumers, in an effort to appear as good providers. However, the large percentage of negative answers provided by participants suggests candid and truthful responses.

## Implications for Future Research

There are several potential areas for future research. First, an estimated 21.6% of consumers on ACT teams were identified as parents, though estimates varied greatly across teams, ranging from 0% to 90% of the total caseload. Given the great variability of estimates, coupled with the significantly higher prevalence rates found in other studies, future research is needed to better assess the number of parent consumers on ACT teams. Specifically, studies should directly ask clients or access client records to determine prevalence rates, rather than making calculations based on ACT provider estimates. Second, additional research that examines ACT team policies for identifying the parental status of consumers and assisting with parent-related issues and needs should be conducted. Though this study found most ACT teams (93.9%) report determining parental status during formal intake/interview, these results do not indicate the consistency or frequency with which teams utilize different identification methods. Furthermore, findings only specify whether providers discuss and help with parentrelated needs, but do not indicate the number of consumers helped or the quality of services consumer receive. Therefore, more rigorous studies of ACT team policies and practices, perhaps through onsite examination of charts, records, and notes, are needed to better understand ACT teams' treatment of parent consumers.

Finally, providers appear to hold relatively negative attitudes and opinions regarding parenting and mental illness, in contrast to the more positive attitudes of parent consumers with SMI. More in-depth analysis of provider thoughts, attitudes, and behaviors is crucial to better understand the perspective of ACT providers. Future research should aim to identify areas of possible bias or misunderstanding among providers, so that programs to inform and educate providers can be designed, which will hopefully result in improved services and treatment for parent consumers of ACT.

### STUDY 2: PARENT CONSUMERS OF ACT

## Introduction

Assertive Community Treatment (ACT) is a community-based intervention to treat individuals with severe mental illness (SMI) who have a history of intensive use of mental health services and difficulties living in the community (Bond, Drake, Mueser, & Latimer, 2001). Teams of ACT providers work together to offer comprehensive, intensive, community-based, and long-term treatment for consumers with SMI. Since the primary treatment objective of ACT is to promote and maintain adaptive functioning of consumers in the community, providers assist with medication, housing, finances, employment, education, and community living issues, as well as provide twenty-four hour a day crisis management (Bond et al., 2001). ACT is effective in reducing consumer hospitalizations, relapses, and symptoms, as well as in increasing consumers' community functioning and overall quality of life (Bond et al., 2001; McGrew, Bond, Dietzen, & McKasson, 1995).

Though the ACT treatment model effectively addresses many realms of community living (e.g. work, housing, substance abuse, etc.), the challenges associated with being a parent are not typically incorporated into ACT treatment services. In fact, because ACT teams do not consistently assess for parental status, they may not even be aware of the parental status of consumers or whether consumers have needs in this area (Gewurtz, Krupa, Eastabrook, & Horgan, 2004; Maybery & Reupert, 2009; Nicholson & Biebel, 2002). ACT research has also tended to ignore parental status as an important client variable. For example, although studies have investigated the impact of various demographic and clinical variables on outcomes, such as age, race, and substance abuse severity, no study has examined the potential impact of parenting on successful treatment

outcomes with ACT (Kortrijk, Mulder, Roosenschoon, & Wiersma, 2010). The absence of parenting in the ACT literature suggests that parenting either does not represent a significant factor in the treatment of SMI, or has been erroneously overlooked in the ACT model's treatment conceptualization. This failure to assess and support the parental needs of consumers is problematic, since consumers with SMI ascribe high importance and value to their role as parents, and want more parent-related treatment services (Nicholson & Deveney, 2009; Diaz-Caneja & Johnson, 2004; Bournsell, 2007). Unfortunately, no studies have systematically examined the perspectives of parent consumers of ACT, so conclusions about the importance of incorporating parenting into the ACT treatment model are not possible. The study will therefore begin to address this gap by exploring the perspectives of ACT parents and the relationship between parenting, severe mental illness, and treatment needs.

### Parents with Severe Mental Illness

Studies conducted in the United States indicate that about one-half of all women and one-third of all men diagnosed with severe mental illness have children (Hinden, Biebel, Nicholson, Henry, & Katz-Leavy, 2006; Nicholson & Biebel, 2002). Studies in other countries have found approximately 63% of women and 26% of men with SMI in London are parents, and roughly 59% of women and 25% of men with SMI in Australia are parents (Boursnell 2007; Diaz-Caneja & Johnson, 2004). These estimates are similar to those reported in the only study to date assessing ACT parents, which found approximately 38% of ACT consumers on four ACT teams in Canada were parents, in which 22% of the caseload were mothers and 16% of the caseload were fathers (Gewurtz et al., 2004). Thus, about one-third to as many as one-half of consumers served by ACT teams may be parents, who may want treatment services tailored to parenting needs.

Parents with SMI face many unique challenges and problems, tied to the dual demands of parenting and managing severe mental illness (Ackerson, 2003; Diaz-Caneja & Johnson, 2004). People with SMI not only experience more significant stressors than adults without SMI, but also face higher rates of separation, divorce, poverty, unemployment, and risk of losing custody of their children. Mothers with SMI are more

likely than healthy mothers to be single mothers and experience higher levels of family strife, stigma, and victimization (Nicholson, Sweeney, & Geller, 1998). Studies estimate that less than half of mothers with SMI receive child support or financial assistance from a spouse, other parent, or family member, and often raise their children below the poverty line (Mowbray, Oyserman, Bybee, MacFarlane, & Rueda-Riedle, 2001). Thus, parents with SMI need to not only manage their mental illness, but often face additional challenges like poverty, unemployment, and lack of social support that pose difficulties for effective functioning in the parenting role, suggesting a need for treatment services to address these concerns.

Interviews conducted with parents with SMI show that despite the stressors associated with being a parent with severe mental illness, they highly value their role as parents (Ackerson, 2003; Nicholson & Deveney, 2009). Parents report feeling competent to provide adequate parenting, emphasizing that being a parent gives them the opportunity to be successful and efficacious in a valued social role (Ackerson, 2003; Oyserman, Bybee, Mowbray, & Kyoung Kahng, 2004). They frequently note positive aspects of being a parent, such as providing purpose in life, increasing self-esteem, helping cope with symptoms, providing a source of efficacy and personal growth experience, and increasing motivation to adhere to treatment and work on relapse prevention (Diaz-Caneja & Johnson, 2004; Oyserman et al., 2004).

Although parents with SMI value their role as parents, they also acknowledge significant challenges associated with caring for children while simultaneously coping with a severe mental illness (Ackerson, 2003; Nicholson et al., 1998). For example, mental illness symptoms and medication side effects may impair abilities to support and care for children (Nicholson et al., 1998; Diaz-Caneja & Johnson, 2004). In addition, parents with SMI worry that their children will be tasked with taking care of the family during their acute episodes of mental illness (Stallard, Norman, Huline-Dickens, Salter, & Cribb, 2004; Wilson & Crowe, 2008). Parents with SMI acknowledge great self-blame, shame, and guilt regarding symptoms and relapses, which causes them to frequently question their parenting abilities, hide their SMI diagnosis, and feel unfairly judged by others as bad parents (Ackerson, 2003; Wilson & Crowe, 2008).

Another serious problem for parents with SMI is loss of custody. Mothers with SMI are about three times more likely than mothers without mental illness to experience child protective services involvement or custody loss (Diaz-Caneja & Johnson, 2004). A U.S. epidemiological study found only 33% of women and 5% of men with SMI have primary custody of all their children, with an estimated 40% of women with SMI holding primary custody of at least one child (McLennan & Ganguli, 1999). Moreover, an estimated 60% to 80% of parents with mental illness have lost custody of at least one of their children, though up to 80% of mothers report some involvement in helping raise at least one of their children (Kundra & Alexander, 2009; Nicholson et al., 1998). These high prevalence rates for loss of custody suggest that parents with SMI face significant difficulties with raising children, experiencing much higher rates of custody problems than the general population.

### Treatment for Parents with Severe Mental Illness

Clearly, the empirical evidence shows that parents with SMI face difficult challenges. Unfortunately, the current treatment system is not meeting their needs. When asked about parenting, parents express great interest in parent-related services, as well as frustration with the system-wide failure to recognize the impact that being a parent has on mental illness and recovery (Boursnell, 2007; Fox, 2009; Mason, 2009). Parents with SMI identify a need for better communication with providers about family issues and more emphasis on parenting in treatment plans and interventions (Chen, 2008; Diaz-Caneja & Johnson, 2004). Additional needs include parenting skills training, therapy with children, practice communicating with children, legal help with custody and child support, and peer support groups with other parents to discuss parenting difficulties (Diaz-Caneja & Johnson, 2004; Cournos & Goldfinger, 2010).

Although parents with severe mental illness feel their parental needs are not being met, they often remain silent about parenting struggles out of fear of being stigmatized or deemed an unfit parent (Fox, 2009; Kundra & Alexander, 2009; Stallard et al., 2004). Parents with SMI report that mental health providers hold demeaning attitudes and low expectations of their parenting abilities, thereby preventing honest discussion of

parenting (Hinshaw, 2005). One study found only 20% of mothers with SMI felt their providers were supportive of their role as mothers (Nicholson & Biebel, 2002). Thus, the fear of stigmatization for having mental illness, and the associated self-blame, renders open discussion of problems difficult (Hinshaw, 2005; Wilson & Crowe, 2008).

### Statement of the Problem

Parents with severe mental illness value their role as parents, but also face distinct parenting challenges indicative of a need for more parent-focused treatment. When offered, family and parent-focused interventions show promise in helping parents with SMI (Reupert & Maybery, 2011). Specifically, preliminary research of the few existing programs for parents with SMI and their children has found that family-centered and community-based programs that emphasize parental strengths rather than weaknesses promote high rates of consumer satisfaction and progress toward desired outcomes, such as crisis management, reproductive health care, safe housing, access to health care, employment, child development knowledge, parenting skills, and social supports (Hinden, Biebel, Nicholson, Henry, & Katz-Leavy, 2006; Nicholson, Hinden, Biebel, Henry, & Katz-Leavy, 2007). However, little information exists concerning the prevalence, needs, and perspectives of parents served by ACT teams. In overlooking the role of parenting in the lives of ACT consumers, the ACT literature has largely ignored many potentially important areas for intervention, including the positive aspects of parenting and whether parenting strengths could be incorporated into treatment planning and relapse prevention to enhance treatment outcomes and recovery (Fudge, Falkov, Kowalenko, & Robinson, 2004; Hinden et al., 2006). Given these gaps in the ACT literature, a study of the perspectives of parents served by ACT is clearly warranted. The current study conducted semi-structured interviews with parents currently being served by ACT teams to examine relevant attitudes, thoughts, and experiences of being a parent with SMI. Specific areas covered included custody issues, the relationship between mental illness and parenting, parenting needs, and satisfaction with ACT service.

# Methodology

# **Participants**

To be included in the study, participants had to be diagnosed with a severe mental illness (e.g. schizophrenia, schizoaffective disorder, bipolar disorder, or major depressive disorder), actively receiving ACT treatment services, and the parent of at least one biological, adopted, or step child. Exclusion criteria included presence of a cognitive disability that would interfere with the participant's ability to understand study questions, current inpatient hospitalization, and/or an active episode of acute symptoms that would preclude participation in the study.

#### Recruitment

To generate the sample, team leaders of five ACT teams in Indiana were contacted, informed about the purpose of the study, and asked to help with recruitment by posting and distributing recruitment flyers to potential participants. Rather than randomly selecting teams, five ACT teams were intentionally selected from 16 ACT teams across Indiana to ensure inclusion of teams from different regions (e.g. northern vs. southern Indiana), settings (e.g. urban, rural, suburban), and consumer demographics (e.g. ethnicity, SES, gender). Three of the five team leaders contacted about the study agreed to allow the researcher to recruit participants for the study. Thus, all participants were recruited from these three ACT teams. The teams included one team from northwest Indiana, one from rural northeast Indiana and one from a large metropolitan area in central Indiana. One team was a large ACT team (10+ team members) serving about 70 consumers, one was a medium size ACT team (7+ team members) serving about 50 consumers, and one was a small ACT team (5 team members serving about 35 consumers. The recruitment goal was to obtain a sample of at least 15-20 participants, with about 5-6 participants from each ACT team.

Given the potentially distressing nature of some of the interview questions, team leaders were advised to focus recruitment efforts on consumers judged to be psychiatrically stable, who would be able to fully understand and participate in the study.

Recruitment materials instructed interested participants to either contact the researcher via phone or email or to inform team leaders of interest in the study. The researcher or team leaders then informed potential participants about the proposed date, time and location for participation. Participants were given a \$25 dollar gift card for completing the one hour-long interview.

#### Measure

A 40 item semi-structured interview, labeled Consumer Interview was created for the study (See Appendix C). Questions included 15 demographic/general questions, 3 questions about ACT treatment/services, and 22 open-ended items about children, parenting, mental illness, and ACT involvement in parenting. Demographic items were designed to obtain basic background information about participants (e.g. age, gender, race, education, diagnosis, employment, etc.) and required one to two word responses. The ACT-specific questions sought information about participant's use of ACT treatment services and length of time on ACT teams.

The remaining open-ended questions about parenting, SMI, and treatment needs sought more personal information and operationalized the list of topics for interviewing mothers with SMI, created by Diaz-Caneja and Johnson (2004). Through a series of three pilot interview studies, Diaz-Caneja and Johnson (2004) created an interview guide for parents with SMI listing main topic areas and a suggested topic order. The guide includes general topic areas (e.g. positive and negative aspects of the experience of motherhood), but does not provide specific interview questions. Questions were created to have relevance for ACT consumers and addressed the following interview guide topics: attitudes about parenting, ways in which children affect adherence to treatment, experiences with social services and custody issues, the types of treatment being received, whether mental health services take parental status into account, the extent to which mental health services meet parenting needs, and suggestions for ways in which services could be improved to better support parents with SMI (Appendix C).

#### Procedure

The first author conducted all interviews individually with participants. Prior to each interview, participants received an informed consent sheet listing a detailed explanation of the purpose and design of the study, as well as the risks and benefits of participation (See Appendix E). Participants were informed of their rights, including the right to confidentiality of answers, refuse to answer questions, take breaks, and terminate the interview early. Permission also was obtained to tape record the interview. As discussed above, semi-structured questions were used to guide interviews. Depending on participant responses, questions were sometimes skipped or asked out of order. Pertinent follow-up and clarification questions not on the operationalized list of questions were asked when necessary. Entire interviews were tape recorded for transcription and analysis. The interviewer also took field notes regarding behavioral observations, nonverbal cues, facial expressions, and/or any unusual occurrences during the interview. At the end of the interviews, participants were debriefed, thanked for taking part in the study, and provided contact information for future questions or concerns (See Appendix F). The Institutional Review Board at Indiana University-Purdue University Indianapolis, IN, approved all the study procedures.

### Setting

All but four interviews were conducted in small office areas, typically used by ACT team members. Four participants were interviewed at their homes due to difficulties arranging transportation to the main office area. Additional residents of the home were asked to leave the room if consumers preferred to conduct, the interviews in private. Only the researcher and participant were present for the interviews, except for one interview in which the participant requested that her significant other be present during the interview.

## Data Analysis

Interviews were tape-recorded and transcribed for data analysis. Participant comments were entered verbatim into a word processing document. The research team (i.e. primary researcher and two research assistants) reviewed transcribed interviews

using a content analysis approach to identify potential themes within the data. Preliminary themes were noted and incorporated into a preliminary codebook, listing the themes and procedures for coding responses. Each member of the research team independently used the codebook to analyze the same transcribed interview. Comparisons across raters identified coding discrepancies and problems, prompting codebook revisions, and a new round of coding analyzing a new interview. Altogether, four rounds of codebook revisions took place, in which themes were eliminated, combined, or expanded, to best capture the data. The final set of themes was included in the final codebook, outlining the coding procedure for the entire participant interview (See Appendix D). The research team then used the codebook to independently code and enter data for the remaining interviews into SPSS. To ensure reliability in coding responses, each team member coded and entered 11-12 interviews, so that all 17 interviews were analyzed by at least two members of the research team.

Open-ended questions were coded according to emergent categories and themes. The number of emergent categories identified ranged from six to nine themes per question. A total of 147 themes were identified across qualitative questions, though this study will focus on 59 themes across the nine questions most relevant to study purpose (Appendix D). Each theme was treated as a separate dummy variable for data entry, with responses coded as either 0 (theme not evident) or 1 (theme present). Participants' responses could be coded as satisfying more than one theme.

Overall, inter-rater reliability between raters as measured using the intraclass correlation (ICC) was acceptable for the vast majority of the themes coded, with values ranging from .230 to 1.00 (See Tables 9, 10, and 11). Forty-four of the 59 themes (74.6%) had good reliability with values of .70 or higher, and eight themes (13.6%) had moderate reliability with values of .60 or higher. The remaining seven themes (11.9%) had poor reliability, with the lowest intraclass reliabilities for four of the "other" themes, including "Mental Illness Impacts Parenting: Other" (ICC = .23, p = .159), "Suggestions for ACT Team: Other" (ICC = .38, p = .332), "Benefits: Other" (ICC = .44, p = .037), and "Parenting Impacts Mental Illness: Other" (ICC = .52, p = .019) (See Tables 9, 10, and 11).

### Results

## **ACT Parent Consumer Sample**

Out of 20 individuals approached for the study, 17 (85%) agreed to participate. Altogether, 11 participants were mothers and 6 participants were fathers with SMI. Interviews ranged from 35-92 minutes in length. Participants were predominately Caucasian (10, 58.8%) and divorced (11, 64.7%) (See Table 6). The primary diagnoses for the sample included 7 participants (41.2.5%) with bipolar disorder, 6 participants (35.3%) with schizophrenia, and 4 participants (23.5%) with schizoaffective disorder. Two of the participants (11.8%) also reported a co-morbid personality disorder. The average age of onset for mental illness was 27.5 years, with approximately 12.3 total hospitalizations per participant (See Table 6).

The majority of participants (12, 70.6%) were receiving disability benefits, with only two parents (11.8%) actively employed with part-time jobs. Most participants (15, 88.2%) had obtained a high school diploma or GED. Roughly half of the sample lived alone (10, 58.8%) in independent housing (9, 52.9%), with 5 participants (29.4%) residing in special housing supervised by the ACT team. On average, participants reported being served by ACT teams for 44.6 months, though there was substantial variability (three months to ten years). The sample reported a long history of high service needs, but was fairly stable psychiatrically at the time of the study. The time since most recent inpatient psychiatric hospitalization, averaged across participants, was 32.6 months. Only one participant (5.9%) had been hospitalized and one participant (5.9%) had been homeless in the month prior to the interviews.

#### Children/Grandchildren of ACT Parents

The parents in the sample had 1 to 9 children, with an average of 2.6 children per participant (See Table 7). However, when the parent with nine children was excluded, the average number of children per parent dropped to 2.2 children. Altogether, participants had 44 children, ranging from 3-44 years of age. Almost all the children (97.7%) were biological offspring and still living; one child (2.3%) was a stepchild and one child (2.3%)

passed away at age 7 in a car accident. In addition, 8 of the 17 participants (47.1%) reported having grandchildren, ranging from 1-21 years of age. Grandparents in the sample had between 1 and 7 grandchildren, averaging 1.6 grandchildren per participant (See Table 7).

Only 2 participants (11.8%) currently had one or more children living with them, though eight parents (47.1%) noted their adult children used to live with them when the children were younger (See Table 8). Across the 43 living children, 21 (48.8%) were adults living on their own, 10 (23.3%) were young children living with the other parent, 5 (11.6%) were young children living with the participant, 5 (11.6%) were young children living with other living with an adoptive/foster family, and 2 (4.7%) were young children living with other relatives. None of the participants were living with their grandchildren (See Table 7).

## Custody

Participants were asked several questions about custody, i.e., loss of custody in the past, time spent with children, and current custody arrangement. Most parents reported custody issues, particularly loss of custody (See Table 8). At the time of the interviews, only two parents (11.8%) had full custody of any of their children, though two additional parents reportedly had full custody of their children when they were under the age of 18. However, both parents currently reporting full custody had experienced loss of custody in the past. In total, fifteen parents (88.2%) lost or gave up custody of their children at some point in the past, with only 2 (11.8%) of these parents successfully gaining back custody, 3 parents (17.6%) retaining partial/shared custody, and 6 parents (35.3%) losing custody permanently (See Table 8).

Consistent with the high rates of custody loss, participant responses to open-ended questions about custody were largely negative. In describing experiences with custody, most parents (14, 82.4%) used extremely negative adjectives like "painful," "traumatic" or "world-shattering" (See Table 9). Specifically, participants talked about several issues, including struggles with separating from children and/or irreparably damaging their relationship with children (14, 82.4%), the legal process (5, 29.4%), feeling confused and oppressed (4, 23.4%), giving up children for adoption (3, 17.6%), fighting to get custody

back (3, 17.6%), and other issues (5, 29.4%) (See Table 9). Despite struggles with custody loss, many participants noted that they still see their children regularly through formal or informal custody arrangements. While four participants (23.53%) have no current contact with their children, two participants (11.8%) reported seeing their children at least once a year and eleven participants (64.7%) reported seeing their children at least once a month (See Table 8).

## Attitudes about Being a Parent

Participants were asked several questions about being a parent with SMI. Overall, all participants expressed positive beliefs and feelings about being a parent with SMI, emphasizing the benefits and joys of parenting. Numerous benefits or "good parts" of parenting were identified, with parents often listing multiple parenting benefits. Specifically, 9 parents (52.9%) mentioned the love given and received by children, 6 (35.3%) discussed spending quality time with children, and 4 parents each (23.5%) talked about raising or teaching children, watching children grow up, strong relationships with their children, and other benefits (e.g. having someone to brag about, being proud, etc) (See Table 10). At the same time, 13 participants (76.5%) acknowledged numerous difficulties with being a parent while managing a SMI, with all these parents recalling past struggles to fulfill the parenting and/or financial responsibilities associated with having a child. Participants also reported other challenges, including separation from children (5, 29.4%), having to provide punishment/discipline (17.6%), getting along with the other parent (17.6%), and other issues like helping with schoolwork and disagreeing with their children (35.3%). In contrast, 4 parents (28.4%) denied having any serious parent-related challenges (See Table 10).

Participants also were asked about the potential relationship between being a parent and having SMI. Three participants (17.6%) rejected the possibility of any impact, stating that one does not affect the other. The remaining participants generally endorsed the belief that SMI negatively impacts parenting, reporting problems associated with volatile mood/symptoms (8, 47.1%), concern about the children's view of their mental health (8, 47.1%), side effects of medication (5, 29.4%), additional stress and worry

caused by SMI (4, 23.5%), and several other concerns (See Table 10). Regarding the alternative relationship of how being a parent potentially impacts mental health, six participants (35.3%) denied that parenting has any impact on mental health and accomplishment. Other parents identified several potentially negative impacts, including exacerbated symptoms (6, 35.5%), changed relationship with children (5, 29.4%), additional stress or worry (3, 17.6%), and a few other impacts like increased financial burden and decreased social life (5, 29.4%). Lastly, participants were asked to consider whether being a parent influences their interest and/or commitment to treatment services. While five participants (29.4%) indicated no relationship, other participants cited their parental status as a great source of motivation (6, 35.3%), or managing their SMI and one participant (5.9%) credited her parenthood as a source of pride as well as the primary reason for seeking treatment (5, 29.4%) (See Table 10).

## **ACT Treatment Services**

Participants were asked several questions about ACT services to determine the types of treatment offered and potential gaps in treatment. Participants listed a wide variety of treatment services provided by these ACT teams, including help with medication (14, 82.4%), finances/payeeship (13, 76.5%), case management (12, 70.6%), therapy/counseling (12, 70.6%), and transportation (11, 64.7%). Though most participants (11, 64.7%) receive treatment solely from the ACT team, six parents (35.3%) mentioned having providers outside the ACT team, with four participants (23.4%) seeing a private psychiatrist for psychiatric medication. Particularly relevant to the study, none of the participants listed family services as part of their treatment, though several participants acknowledged the option of family therapy through the ACT team if interested.

## Needs of ACT Parents

Participants also discussed their parenting needs and satisfaction with ACT services in addressing their needs (See Table 11). About half of the parents (9, 52.9%) denied having any significant parenting needs or were unable to generate any examples of needs at the time of the interview. The remaining parents reported several general

parenting needs, such as family therapy (7, 41.2%), finances/resources for children (6, 35.3%), communication with children (5, 29.4%), social and emotional support from other parents (4, 23.5%), and several additional needs (4, 23.5%) (e.g. transportation to see children, liaison between participant and adoptive family).

When asked whether ACT services addressed their needs, parents' responses were mixed. Overall, five parents (35.3%) expressed satisfaction with ACT teams meeting their needs as parents, five parents (29.4%) were unsure, and three parents (17.6%) expressed disappointment (See Table 11). When parents were asked to rate satisfaction with ACT in addressing parenting needs using a five-point scale (1=totally dissatisfied; 5=totally satisfied), the mean rating was 3.94, with 4 participants selecting 3 (neutral, 23.5%), 7 participants selecting 4 (satisfied, 41.7%), and 5 participants selecting 5 (highly satisfied, 29.4%) on the scale. Participants' satisfaction ratings differed slightly depending on the team providing services. Specifically, the 7 participants being served by the team in northwest IN had an average rating of 4.0, the 6 participants being served by the team in central Indiana had an average rating of 3.25. Differences across teams were not significant, F (2, 14) = 1.98, p = .174, however the analysis was underpowered.

When prompted to explain ratings, about half of the participants (52.9%) listed positive aspects of the team, such as "they help me with my children" or "she praises me when I visit with my children." In contrast, seven participants (41.2%) listed negative aspects of the ACT team, such as "you would think I could tell them about it, but I can't" and "they've never like ever tried to even go there period with me." Finally, two participants (11.8%) noted that their satisfaction with the ACT team depends on the specific ACT staff member (See Table 11).

Interestingly, the overall sample was almost evenly split between 8 parents (47.1%) with adult children and 9 parents (52.9%) with minor children under the age of 18 (See Table 7). The participants' children were also evenly split, with 21 (48.8%) adult children and 22 (51.2%) minor children. Regarding parenting needs met by ACT services, most participants with no unmet needs were parents of adult children living

independently of participants. For the 8 parents of adult children, 1 parent (12.5%) reported unmet needs and 7 parents (87.5%) reported no unmet needs. In contrast, for the 9 parents of minor children, 7 parents (77.8%) reported unmet needs and 2 parents (22.2%) reported no unmet needs (See Figure 1). A chi-square analysis between parent group (0 = parent of minor child, 1 = parent of adult child) and unmet needs (0 = no needs, 1 = unmet needs) was significant ( $\chi^2(1)$ = 7.24, p = .007), suggesting significant differences across parental group for whether ACT teams meet parent-related needs. Similar differences across parent groups were found for overall satisfaction ratings. The average satisfaction rating for parents of adult children was 4.63 out of 5, whereas the average rating for parents of minor children was 3.78 out of 5, though a t-test comparing parents of minors and parents of adults on overall satisfaction with ACT services (1 – 5) was not significant (t(15) = -.785, p = .445) (See Figure 2).

# Suggestions of ACT Parents

Participants were asked if they had suggestions to improve treatment services for parents with SMI. Participants identified several parent-related issues and needs that ACT teams should consider incorporating into treatment services. Specifically, participants said ACT providers should focus on helping consumers communicate/bond with their children (6, 35.3%), family therapy (6, 35.3%), resources for children (6. 35.3%), transportation to visit children (6, 35.3%), custody issues (3, 17.6%), social skills (3, 17.6%), activities to do with children (3, 17.6%), and other parenting needs like schoolwork, housing, financial, etc. (4, 23.5%). When asked about general suggestions for improving ACT treatment services, slightly less than half of participants (7, 41.2%) expressed contentment with the ACT team and offered no suggestions for improvement. The same number of participants (7, 41.2%) suggested improvements to non-parent related services, such as better transportation, more help with finances, and better housing choices. Altogether, the majority of participants (14, 76.5%) reported being comfortable with making suggestions to ACT team members and several participants (3, 17.6%) mentioned intentions to talk to ACT providers about topics discussed in the interviews, particularly in regards to incorporating family therapy into treatment.

### Discussion

### Parent Consumers of ACT

The perspectives of ACT parents interviewed in the study support previous findings regarding the unique needs, challenges, and experiences of parents with severe mental illness. Compared to parents without SMI, consumers with SMI face higher rates of divorce, separation, lack of social support, unemployment, and poverty (Mowbray et al., 2001; Ackerson 2003). All these findings proved true in the study. Of the 17 ACT parents interviewed, only 2 parents (11.8%) were in a relationship with a significant other, 2 parents (11.8%) had part-time jobs, and most reported extreme financial difficulties and general dissatisfaction with levels of social support. Several parents reported not having enough money to support children, citing money as a key barrier to preventing them from being more involved in their children's lives.

## Custody

As expected, legal issues and loss of custody emerged as a significant challenge for ACT parents. For the current sample, 15 parents (88.2%) reportedly lost custody at least once, and only 16.7% of fathers (1 of 6) and 9.1% of mothers (1 of 11) had primary custody at the time of the interviews. These findings are consistent with other studies, which estimate as many as 60%-80% of parents lose custody of their children at some point in time (Kundra & Alexander, 2009; Mowbray et al., 2001). Across the study interviews, ACT parents consistently expressed negative attitudes about custody issues, emphasizing how traumatic and painful the experiences were, how custody loss damaged their relationship with their children, and increased feelings of shame and oppression. Over half of the participants complained about lack of child support from the other parent and/or family members, as well as the stress of providing for children without adequate financial resources. These findings indicate that ACT parents are similar to other parents with SMI (Diaz-Caneja & Johnson, 2004; Fox, 2009; Kundra & Alexander, 2009; Stallard et al., 2004) and highlight the importance of addressing custody issues in treatment and the need for ACT providers to offer assistance with custody.

## **Attitudes about Parenting**

As found in other studies of parents with SMI, ACT parents hold both positive and negative attitudes regarding parenting (Diaz-Caneja & Johnson, 2004; Boursnell 2007). Every parent was able to identify at least one parenting benefit or reward, such as having a child to love, teach, and spend time with regularly, as well as viewing their role as parents as a reason and motivation to adhere to treatment. At the same time, most parents acknowledged the difficulties of being a parent with SMI. Specifically, SMI often negatively impacts parenting, due to parenting/financial responsibilities, SMI symptoms, medication side effects, stress associated with treating SMI, and concern about children's disapproving views of SMI.

# Parenting Needs

When exploring the needs of parents being served by ACT, results were somewhat surprising. About half of all participants denied having any significant unmet parenting needs and reported general satisfaction with ACT services. Given the challenges participants discussed about being a parent with SMI, as well as studies indicating many unmet needs of parents with SMI, the large number of parents expressing no serious parenting needs was unexpected (Mowbray et al., 2001; Ackerson 2008, Boursnell 2007). However, needs appeared to be a function of age of children. The majority of participants with adult children (7 of 8, 87.5%) reported no unmet needs whereas the majority of parents with young children (8 of 9, 77.8%) reported parenting needs not being addressed by ACT Services, with significant differences across groups for met versus unmet parenting needs (See Figure 1). The notable asymmetry in these results, coupled with the frequency of different participant response themes, suggest that parents of adult children may have less needs because they no longer face the serious parenting needs common to parents of young, dependent children, such as having to provide housing, food, transportation, clothing, school assistance, custody, etc.

Altogether, the findings suggest parents with minor children tend to have more unmet parenting needs and higher dissatisfaction with ACT, compared to parents of adult children, though differences in satisfaction ratings were not significant. Unfortunately,

study findings are based on a small sample of parents with adult children and minor children, so results may reflect an underestimate of the true needs of parents actively raising children due to the inclusion of parents with adult children. However, the study did identify particular areas of unmet parenting needs, including family-based therapy, parenting skills, communication with children, resources/finances for children, and social support from peers. Parents with SMI have consistently mentioned these needs across numerous studies; strongly suggesting ACT providers may need to explore these issues with clients (Diaz-Caneja & Johnson, 2004; Boursnell 2007; Nicholson et al., 1998). Therefore, while the ACT treatment model appears to be adequately serving parents of older, independent children, it may not be adequately addressing parents of young, dependent children. ACT providers should consider the parental status of parents with minor children and incorporate services addressing key parenting needs, such as custody, communication/bonding with children, parenting skills, resources for children, and peer support. Incorporating these issues into treatment is likely to result in improved outcomes for parents with severe mental illness.

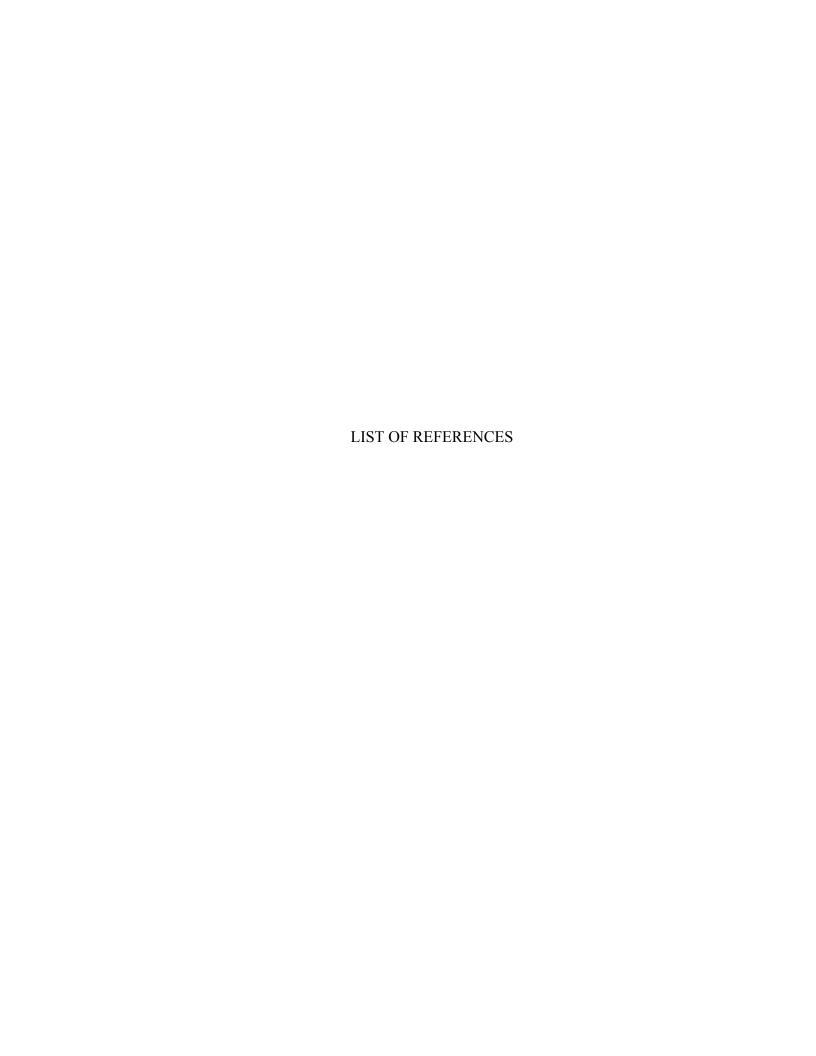
# Study 2 Limitations

The study has several important limitations. First, the sample was small, participants were not randomly selected from a large pool of ACT parents, and only psychiatrically stable consumers were included in the study, thereby limiting the generalizability of findings. Also, it is unknown if certain ACT parents declined to volunteer for the study, due to the sensitive nature of the interview topic and questions. Parents currently involved in a custody dispute or concerned about potential loss of custody may have intentionally refrained from volunteering. However, this seems an unlikely possibility since team leaders did not report any resistance from consumers during recruitment efforts and the researcher is not aware of any participant declining to take part in the study.

Second, the construct validity of the interview measure is unknown. The interview questions were created for the study and although they were based on prior work and thus had content validity, the researchers are unable to establish criterion or

construct validity. Thus, the underlying constructs intended to be measured and examined in the study may not have actually been measured and examined.

Finally, no mechanism exists to ensure participants responded accurately and truthfully to interview questions. Without a procedure for confirming the information gathered, such as seeking confirmation from participants' family, friends, or ACT team providers, the study is limited to self-reported information. However, the researcher made every effort to repeat, rephrase, and clarify questions to ensure participants understood what was being asked, so it seems unlikely participants did not understand the questions. Further, the numerous admissions made by participants regarding negative thoughts and behaviors (e.g. getting arrested, drug use, losing custody) suggest participants were being honest and truthful. Thus, despite some limitations, the study appears to have successfully captured the thoughts, experiences, and needs of this group of parent consumers served by ACT.



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Table 1
Study 1 ACT Provider Sample

	Frequency (%)
Participant Role	• • • • • •
Team Leader	32 (39.0%)
Social Worker	30 (36.6%)
Substance Abuse Specialist	16 (19.5%)
Case Manager	15 (18.3%)
Psychologists/Counselors	10 (12.2%)
Nurses	7 (8.5%)
Managers/Administrators	5 (6.1%)
Peer Consumers	2 (2.4%)
Other	7 (8.5%)
Total	85
Team Leader Role	
Social Worker	33 (40.2%)
Psychologist/Counselor	15 (18.3%)
Nurse	5 (6.1%)
Administrator	3 (3.7%)
Substance Abuse Specialist	2 (2.4%)
Case Manager	1 (1.2%)
Other/Missing	23 (28.1%)
Type of City	
Urban Large City	41 (50%)
Mixed	19 (23.2%)
Urban Small City	10 (12.2%)
Rural	5 (6.1%)
Suburban	2 (2.4%)
Other/Missing	5 (6.1%)

Table 2

Team and Caseload Characteristics Across 76 ACT Teams

	Mean (SD)	Range
Team Characteristics		
Caseload Size	76.5 (46.5)	2 - 350
Team Size	10.4 (3.8)	3 - 25
Caseload/Team Size Ratio	7.8 (3.5)	1.5 - 26.9
Caseload Characteristics		
Female	41.3% (16.1)	0.0% - 83%
Caucasian	54.9% (31.7)	0.0% - 100%
African American	30.2% (28.3)	0.0% - 90%
Hispanic	8.6% (31.7)	0.0% - 100%
Other Races	4.3% (17.1)	0.0% - 82%

Table 3

Parenting Prevalence Rates Across 76 ACT teams

	Frequency (%) N = 5766	95% CI	Range Across Teams
Parents	1247 (21.6%)	20.6% - 22.7%	0.0% - 90%
Female Parents	1037 (18.1%)	17.1% - 19.2%	0.0% - 90%
Male Parents	210 (3.6%)	3.2% - 4.2%	0.0% - 90%
Unsure of Parental Status	369 (6.4%)	5.8% - 7.1%	0.0% - 80%
Consumers Want Children	696 (12.1%)	11.2% - 12.9%	0.0% - 100%
Unsure if Consumers Want	821 (14.2%)	13.3% - 15.1%	0.0% - 100%
More Children	•		

Table 4

Assessment of Parental Status

	Frequency (%)
	N = 82
Methods	
Formal Intake Form/Intake Interview	38 (46.3%)
Assessments	24 (29.3%)
Consumer Self-Report	20 (24.4%)
Consumer Records/Previous Treatment History	16 (19.5%)
Referral	12 (14.6%)
Pregnant/Children Present	4 (4.9%)
Other	7 (8.5%)
Options	
Formally at Intake	74 (93.9%)
Informally Learn about Status During Treatment	38 (46.3%)
During Discussion of Goals	37 (45.1%)
Formally at Annual Assessments	32 (39.0%)
Referral Source	5 (6.1%)
Do Not Ask	2 (2.4%)
Other	5 (6.1%)

Table 5

Qualitative Themes

	Eng gay on avy (0/)	Internation
	Frequency (%) $N = 82$	Inter-rater
Comfortable Discussing Parenting	N - 62	Reliability .84
Comfortable Discussing Parenting	26 (21 70/)	.84 .79
Provider Training	26 (31.7%)	.83
Part of Treatment and Recovery	20 (24.4%)	.83 .82
Parenting is Important Part of Life	18 (22.0%)	
Depends on Consumer	9 (11.0%)	1.0
Consumers Ask to Discuss Issues	8 (9.8%)	1.0
Good Therapeutic Alliance	7 (8.5%)	.82
No Explanation	5 (6.1%)	1.0
Other	5 (6.1%)	.42
Missing	2 (2.4%)	
Challenges		.75
Sensitive Issue/Defensive Consumer	21 (25.6%)	.77
Custody	16 (19.5%)	.85
Poor Parenting Skills	13 (15.9%)	.67
Staff Barriers	13 (15.9%)	.75
Unawareness of How to Be Parent	12 (14.6%)	.72
Mental Illness/Substance Abuse	11 (13.4%)	.95
Bad Models	7 (8.5%)	.82
Stigma or Guilt	7 (8.5%)	.78
Can be Good Parents	6 (7.3%)	.79
Lack of Resources	6 (7.3%)	.92
Other	5 (6.1%)	.26
Missing	4 (4.9%)	
Advantages		.73
Efficacy and Self-Esteem	29 (35.4%)	.75
Parenting Skills	28 (33.3%)	.90
Therapeutic Alliance/Supports	24 (29.3%)	.46
Consumers	,	
Improves Relationships with	18 (22.0%)	.79
Children	,	
Stress	6 (7.3%)	.79
Safety of Home	5 (6.1%)	.76
Other	8 (9.8%)	.63
Missing	6 (7.3%)	

Table 5 Cont.

Qualitative Themes

	Frequency (%)	Inter-rater
	N = 82	Reliability
Parenting Affects Mental Health		.98
Negative Response	44 (53.7%)	.98
Mixed Response	24 (29.3%)	.98
Positive Response	5 (6.1%)	.98
Themes		.76
Source of Stress/Burden	40 (48.8%)	.79
Increases Symptoms/Exacerbates SMI	32 (39.0%)	.62
Positive Impact	12 (14.6%)	.71
Source of Motivation/Aids Recovery	10 (12.2%)	.89
Causes Problems for Children	7 (8.5%)	.92
Increases Responsibilities of Consumers	6 (7.3%)	.78
Stigma	5 (6.1%)	.71
Lack of Resources	3 (3.7%)	.65
Other	13 (15.9%)	.76
Missing	6 (7.3%)	
Mental Illness Affects Parenting		.87
Negative Response	46 (56.5%)	.87
Mixed Response	25 (30.5%)	.87
Positive Response	7 (8.5%)	.87
Themes		.72
Reduces Parent Abilities/Skills Deficits	44 (53.7%)	.65
Depends on Consumer	22 (26.8%)	.72
Depends on Support Network/ Involvement in Treatment	9 (11.0%)	.94
Positive Impact	9 (11.0%)	.86
Causes Problems for Children	9 (11.0%)	.71
Source of Stress/Additional Burden	7 (8.5%)	.81
Reduces Resources/Finances	5 (6.1%)	1.0
Stigma	4 (4.9%)	.74
Recovery or Treatment	2 (2.4%)	.38
Other	11 (13.4%)	.35
Missing	3 (3.7%)	

Table 6
Study 2 ACT Parent Consumer Sample

	Frequency (%)
	N = 17
Age	47.9 (9.3)
Gender	
Female	11 (63.7%)
Male	6 (35.3%)
Race	
Caucasian	10 (58.8%)
Multiple Races	3 (17.6%)
Asian	2 (11.8%)
African American	1 (5.9%)
American Indian/Pacific Islander	1 (5.9%)
Hispanic	2 (11.8%)
Non-Hispanic	15 (88.2%)
Marital Status	
Divorced	11 (64.7%)
Single/Not Currently in Relationship	5 (29.9%)
Currently in Relationship	2 (11.8%)
Widowed	1 (5.9%)
Married	0 (0%)
Diagnosis	
Bipolar Disorder	7 (41.2%)
Schizophrenia	6 (35.3%)
Schizoaffective	4 (23.5%)
Co-morbid Personality Disorder	2 (11.8%)
Total Hospitalizations	12.3 (18.4)
Months Since Hospitalization	32.6 (41.5)
Months Since Joining ACT	44.6 (33.7)
Education	,
HS Diploma or GED	7 (41.2%)
Some College	5 (29.4%)
No Diploma/GED	4 (23.5%)
Vocational Training Certificate	1 (5.9%)
Employment	
Disability/Benefits	12 (70.6%)
Unemployed	3 (17.6%)
Part-Time	2 (11.8%)
Volunteer	1 (5.9%)

Table 6 Cont.

Study 2 ACT Parent Consumer Sample

	Frequency (%)
	N = 17
Independent Living	9 (52.9%)
Supervised Apartment Program	5 (29.4%)
Living with Relatives/Group Home	3 (17.6%)
Participant Lives With	
Alone	10 (58.8%)
Significant Other	2 (11.8%)
Residents	2 (11.8%)
Parents/Siblings	2 (11.8%)
Roommate	1 (5.9%)
Living Environment	
Rural, Northeast Indiana	7 (41.2%)
City or Suburb, Northwest Indiana	6 (35.3%)
City or Suburb, Central Indiana	4 (23.5%)

Table 7

Children and Grandchildren of Participants

	Frequency (%)
	OR Mean (SD)
Total Children For All Participants	44
Participants with Minor Children	6 (35.3%)
(Under 18)	0 (33.370)
With Minor and Adult children	3 (17.6%)
With Adult Children Only	8 (47.1%)
Number of Children per Participant	2.6 (1.9)
Range	1 - 9 children
Age of Children (N = 43)	22.2 (12.0)
Range	3 - 44 years
Minor Children (Under Age 18)	22 (51.2%)
Adult Children	21 (48.8%)
Gender of Children	N = 44
Male	20 (45.5%)
Female	24 (54.6%)
Relationship of Children	N = 44
Biological	43 (97.7%)
Stepchild	1 (2.3%)
Participants Living with Children	2 (11.8%)
Previously Lived with Children	8 (47.1%)
Residence of Children	N = 43
Child is Adult	21 (48.8%)
Other Parent	10 (23.3%)
With Participant	5 (11.6%)
Adoptive/Foster Family	5 (11.6%)
Other Family Member	2 (4.7%)
Participants with Grandchildren	8 (47.1%)
Total Number of Grandchildren	25
Number per Participant	1.56
Range	1 - 7 grandchildren
Age of Grandchildren	7.5 (6.9)
Range	1 - 21 years
Gender of Grandchildren	N = 25
Male	9 (36%)
Female	16 (64%)
Participants Living with Grandchildren	0 (0%)

Table 8

Participant Contact and Custody of Children

	Frequency (%) of Parents (N = 17)	Frequency (%) of Children (N = 43)
Custody of Children		
Full Custody	2 (11.8%)	6 (13.9%)
Partial Custody	2 (11.8%)	3 (7.0%)
No Custody - No Contact	1 (5.9%)	6 (14.0%)
No Custody - Contact	1 (5.9%)	4 (9.3%)
Adoption/Foster family	3 (17.6%)	4 (9.3%)
Children are Adults (Had	2 (11.8%)	4 (9.3%)
Custody)	` ,	
Children are Adults (Lost	5 (29.4%)	12 (27.9%)
Custody)	` ,	, ,
Children are Adults (No	1 (5.9%)	4 (9.3%)
Custody)	` ,	
Custody Loss		
Retained Full Custody	2 (11.8%)	11 (25.6%)
Retained Partial Custody	3 (17.6%)	8 (18.6%)
Lost Custody - Got it Back	2 (11.8%)	7 (16.3%)
Lost Custody - Permanently	6 (35.3%)	11 (25.6%)
Adoption	4 (23.5%)	6 (14.0%)
Custody Arrangement		
Adoption	2 (11.8%)	5 (11.3%)
No Arrangement - No Contact	2 (11.8%)	8 (18.6%)
Arrangement - Partial Custody	2 (11.8%)	4 (9.3%)
Full Custody	2 (11.8%)	6 (14.0%)
Child is Adult - No Contact	2 (11.8%)	2 (4.7%)
Child is Adult – Contact	7 (41.1%)	18 (41.9%)
Participant Contact with Children		
None	4 (23.5%)	10 (23.3%)
Once a Year	1 (5.9%)	3 (7.0%)
Several Times a Year (3 - 6)	1 (5.9%)	7 (16.3%)
At Least Once a Month	2 (11.8%)	5 (11.3%)
Several Times a Month	3 (17.6%)	10 (23.3%)
Once or More a Week	4 (23.5%)	3 (7.0%)
Everyday	2 (11.8%)	5 (11.6%)

Table 9

Experiences with Custody

	Frequency (%)	Inter-rater
	N = 17	reliability
Experiences with Custody		.85
Painful Experience	14 (82.4%)	.86
Separation/Affected	14 (82.4%)	.62
Relationship		
Legal Problems	5 (29.4%)	.75
Confusing Experience	4 (23.5%)	.53
Gave up Custody (Adoption)	3 (17.6%)	.83
Lost Custody, But Got it Back	3 (17.6%)	1.0
Always Had Custody	3 (17.6%)	1.0
No Answer	2 (11.8%)	1.0
Other	5 (29.4%)	.71

Table 10

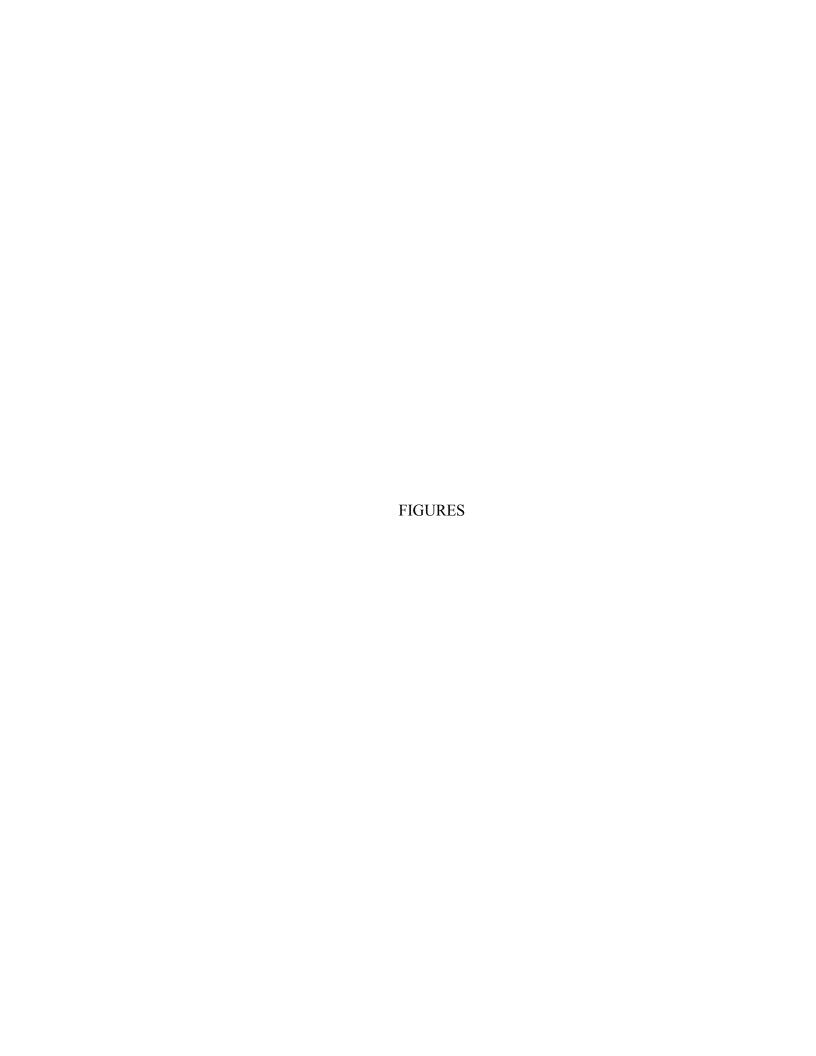
Participant Attitudes and Beliefs

	Frequency (%)	Inter-rater
	N = 17	reliability
Benefits/Good Parts of Parenting	-	.86
Love Given and Received	9 (52.9%)	1.0
Spending Time with Children	6 (35.3%)	1.0
Raising/Teaching Children	4 (23.5%)	1.0
Watching Children Grow Up	4 (23.5%)	.83
Relationship with Children	4 (23.5%)	.63
Spoiling/Give Gifts	2 (11.8%)	1.0
Effect Children's Lives	2 (11.8%)	1.0
Other	4 (23.5%)	.44
Challenges/Hard Parts of Parenting	,	.84
Responsibilities/Finances	13 (76.5%)	.62
Separation from Children	5 (29.4%)	.57
Punishment/Discipline	3 (17.6%)	1.0
No Challenges	4 (23.5%)	1.0
Getting Along with Other	3 (17.6%)	1.0
Parent/Family Members	,	
Seeing Child in Pain	1 (5.90%)	1.0
Other	6 (35.3%)	1.0
Mental Illness Impacts Parenting	,	.76
Mood/Symptoms	8 (47.1%)	.89
Children's View of Parent	8 (47.1%)	.63
Medication - Side Effects	5 (29.4%)	.46
Added Stress/Worry	4 (23.5%)	.83
No Concern About Impact	3 (17.6%)	1.0
Other	3 (17.6%)	.23
Parenting Impacts Mental Illness	,	.86
Symptoms	6 (35.3%)	.87
No Impact	6 (35.3%)	1.0
Relationship with Children	5 (29.4%)	1.0
Added Stress/Problems	3 (17.6%)	.77
No Answer	2 (11.8%)	.87
Source of Pride/Accomplishment	1 (5.9%)	1.0
Other	5 (29.4%)	.52
Parenting Impacts Treatment	, ,	.82
Source of Motivation	6 (35.3%)	1.0
No Impact	5 (29.4%)	.85
Reason for Therapy/Counseling	4 (23.5%)	.83
Don't Need Treatment	1 (5.9%)	.65

Table 11

Parenting Needs

	Frequency (%)	Inter-rater
	N = 17	reliability
Parenting Needs		.86
Family Services/Therapy	7 (41.2%)	.88
Have No Needs	7 (41.2%)	1.0
Financial/Resources	6 (35.3%)	.88
Communication with Children	5 (29.4%)	.85
Support (Emotional, Social)	4 (23.5%)	.63
Don't Know/Never Had Custody	4 (23.5%)	.48
Custody Needs	3 (17.6%)	1.0
Other	4 (23.5%)	.86
ACT Meeting Parenting Needs?		.86
Yes	6 (35.3%)	.89
Sometimes	5 (29.4%)	.69
No	3 (17.6%)	1.0
No Answer	3 (17.6%)	1.0
Satisfaction with ACT (1 - 5)	Mean = $3.94 (.90)$	1.0
Reasons for Satisfaction Rating of ACT		.87
Positive Aspects of Team	9 (52.9%)	1.0
Negative Aspects of Team	7 (41.2%)	.78
Depends on Provider	2 (11.8%)	.65
No Answer/Don't Know	2 (11.8%)	1.0
Other	3 (17.6%)	.83



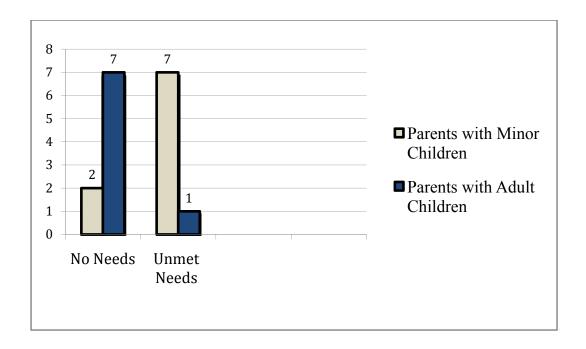


Figure 1. Number of Parents with Parenting Needs Across Parenting Group

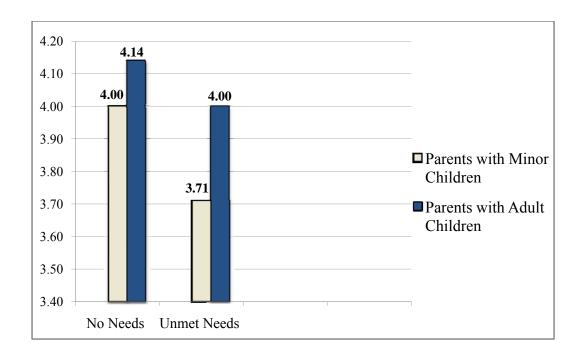


Figure 2. Average Satisfaction (1 - 5) with ACT Services



## Appendix A. ACT Team Survey

•	rs does your team currently se ters, how many are <b>female</b> co			
	•			
2. What is the racial make-up of the consumers served by your team?  How many consumers are African Americans?				
	umers are Caucasians?	•		
_	umers are Hispanic/Latino/La	tinas?		
How many are o	-			
110 11 11111111111111111111111111111111				
3. How do you typically	y find out about the parental s	tatus of the consumer	s you serve?	
ways. Below are some of that describe how your to a formally ask about programmed and a formally ask about programmed about parental and a formally learn about parental and a formally learn about programmed and a formally learn and a f	parental status during annual a status during discussion of tr ut parental status sometime d about parental status of const	check any of the followall boxes that apply). Initial assessment assessment assessment assessment goals aring treatment amers	wing options	
Consumer desire to be in	n a committed relationship wi	th a partner		
☐ Never	Occasionally	Often	☐ Always	
	n a sexual relationship with a			
☐ Never	Occasionally	☐ Often	∐ Always	
Consumer desire to have		Π oa	☐ A1	
Never	☐ Occasionally	Often	∐ Always	
Family planning method		Often	A lyvova	
Never Safe sexual practices	Occasionally	☐ Often	Always	
Never	Occasionally	Often	Always	
	es (financial, resources, babys		Aiways	
Never	Occasionally	Often	Always	
	n communicating/interacting v		личауз	
Never	Occasionally	Often	Always	
Custody issues				
Never	Occasionally	Often	Always	

6. If you do discuss these issues, briefly describe how you address these issues with consumers?
7. Do you feel comfortable discussing parenting issues with consumers? Why or why not
8. What do you think are the biggest challenges or barriers to addressing parenting issues with consumers?
9. How do you think parenting affects mental health and illness?
10. How do you think mental illness affects people's ability to parent?
11. What do you think are the positive aspects of addressing parenting issues with consumers?
12. Does your team provide special programs/services designed for parents? (yes/no) 12.a. If yes, briefly describe such programs:
13. Does your team help consumers with any of the following parent-related needs?  (Please check all boxes that apply)  Day care/babysitter  Food for children  Medical needs of children  Transportation/car seats for children  Disciplining children  13.a.  Other:  Other of the following parent-related needs?  Court appointments/custody issues  Housing for children  Clothing/toys/personal items for children  Helping children with schoolwork  Communicating/interacting with children

14. How many of your consumers are paren	nts/caretakers of children (biological, step,
adopted, or foster)?	-1-9
How many of these parents are <b>fema</b>	
How many consumers are you unsur	<u>.</u>
15. How many consumers (with and without	
How many consumers are you unsur	re if they want to have children?
16. Please check your role on the team:	
Psychiatrist	Nurse Practitioner
Psychologist	Social Worker
Substance Abuse Therapist	Occupational Therapist
Registered Nurse	Licensed Practical Nurse
Case Manager	Consumer/Peer Provider
16.a. Other (please describe):	Consumer/1 cer i rovider
10.a Other (picase describe).	
17. Please check any of the following degre	ees vou have earned
MD (Psychiatry)	MD (Non-Psychiatry)
PhD (Psychology)	PhD (Non-Psychology)
Psy D	NP
RN	LPN
Masters (Psychology)	Masters (Non-Psychology)
Bachelors (Psychology)	Bachelors (Non-Psychology)
17.a. Other (please describe):	Bucherors (1 ton 1 sychology)
18. Are you the team leader of the ACT tea	am in which you serve? (yes/no)
18.a. If not the team leader, please indi	The state of the s
, r	room room room room room room room room
19. How many staff members are on the tea	am?
,	
20. Please check the type of city in which t	he team serves. (Please check only ONE box)
Rural (population less than 2,500)	
☐ Mixed (rural and urban)	
Urban (small city with population less th	nan 50,000)
Urban (large city with population more t	than 50,000)
Suburban (within 20-30 miles of a city)	
20.a. Other (please describe):	
- /	
21. State in which ACT team serves:	

## Appendix B. ACT Team Survey Codebook

Code as answers given; Code -9 for Missing; Code -8 for Unsure/Do not Know				
1. How many consumers does your team currently serve?  Of these consumers, how many are <b>female</b> consumers?				
How many consumers are African Americans?				
How many consumers are Caucasians?				
How many consumers are Hispanic/Latino/Latinas? How many are other race(s)?				
Trow many are other race(s):				
3. How do you typically find out about the parental status of the consumers you serve?				
Code -9 as missing; Code according to themes (can fit more than one theme):				
- Intake - intake interview, ask them				
<ul> <li>Records - history information, hospital records, records from past service providers, charts</li> </ul>				
- Assessment - assessments like behavioral health assessment, psychosocial, etc.				
- Self-report - through interaction with consumers, conversation				
- Referral - referral sources like court, DHS, Child's Protective Services				
<ul><li>Have children with them - pregnant, observe family dynamics in community</li><li>Other</li></ul>				
4. ACT teams find out whether their consumers are parents in a number of different ways. Below are some common approaches, please check any of the following options that describe how your team usually does this (check all boxes that apply).  For check boxes – Code 0 for no checked box; Code 1 for checked box  Formally ask about parental status during intake/initial assessment				
4.a. If yes, how do you ask?				
answers according to themes:				
- Ask directly about children - Do you have children? (or similar question)				
- Specifics or details about children - How many children do you have? How old are they? Do they live with you? What are their names?				
- Functioning of children - How are your children doing? How is relationship?				
- Family structure, composition, relationship - How many people in your family?				
- Involvement with children - Are they involved in your life? Custody status? Time spent with them?				
<ul><li>Assessment or intake - Demographic data collection/questionnaire</li><li>Other</li></ul>				
Formally ask about parental status during annual assessments  Learn about parental status during discussion of treatment goals:				

☐ Informally learn about par ☐ We usually do not learn al ☐ Other (please describe):		_	
Code 0 = no answer; Code -9 for missing (if box checked); Code answers according			
to following themes:	y for missing (if box	checked), code i	inswers according
- Referral source - DHS	S		
- Family/past records			
- Other - See them at he	ome, State that X% ha	ave children	
5. In your role on the team, he consumers?  Code 1 for Never; Code 2 for	•		_
Consumer desire to be in a co	<u> </u>		uc 4 for muys.
Never	Occasionally	Often	Always
Consumer desire to be in a se			
Never	Occasionally	Often	Always
Consumer desire to have chil	dren	_	
☐ Never	☐ Occasionally	Often	Always
Family planning methods			
☐ Never	Occasionally	Often	Always
Safe sexual practices			
Never	Occasionally	Often	Always
Parenting responsibilities (fir			
Never	Occasionally	Often	Always
Parenting problems with com	<u> </u>	•	□ A1
Never	Occasionally	Often	Always
Custody issues		Often	☐ A 1
Never	Occasionally		Always
For questions 6-11 - Code -9 6. If you do discuss these iss consumers?	<u> </u>	<u> </u>	
Themes (can be coded unde	er multiple themes).		

- Intake/Assessment
- Type of conversation anything that refers to way of talking with consumer Examples:
  - Let client direct conversation (client centered)
  - Converse in supportive, positive way, empower clients
- Therapy talking during session, treatment planning, goals, recovery, etc.
- Provide resources
  - Examples:
  - Address issues of safe sex

- Offer condoms/Birth control
- AIDS/STD testing
- Team discussions or team meetings
- Not applicable Children are grown, Don't have children
- Other
- 7. Do you feel comfortable discussing parenting issues with consumers? Why or why not?

 $1^{st}$  part: Code 0 = no, 1 = maybe, 2 = yes

## 2<sup>nd</sup> part: Themes (can be coded under multiple themes):

- Population/Consumer Characteristics - includes comments about not serving parents

### Examples:

- Depends on the consumer
- Sometimes I find it more difficult to talk about when consumer is actively psychotic and we are discussing reunification
- Yes, most of the clients I work with are age 50+
- Yes, risk management: young mentally ill clients having children is often problematic
- Consumers ask or want to talk about parenting
  - Consumers bring it up
- Helps with consumer recovery/treatment
  - Yes clients like speaking about children source of pride
  - Yes because parenting, usually custody issues, can be very relevant to current stage of recovery
  - Yes, it is beneficial to recovery for the client and the children
- Parenting is part of life, normal need for everyone
  - Yes, part of their life, necessary to talk about
  - Yes, because it is a part of the client's system
  - Yes, I'm comfortable because I know it's an important issue that needs to be addressed
  - Yes, because the concerns, problems and accomplishments are very important real life issues
- Provider's Perspective training/part of program philosophy, experience and skills of provider
  - Yes, history in working with children in OCS custody and families with children/adolescents having school issues
  - Yes, because it is part of what we do and I have experience in working with families
  - Yes, my undergrad is in developmental psychology
  - My background is in marriage and family therapy
- Provider has children or consumer is a parent

- Alliance with client/comfort discussing issues
  - Yes, I normally have a good rapport with my consumers
  - Absolutely- our team is very comfortable with discussing any issue presented by consumer
  - Yes, good therapeutic relationship
- No explanation just answer yes or no
- Other
- 8. What do you think are the biggest challenges or barriers to addressing parenting issues with consumers?

# $1^{st}$ part: Code 0 = negative, 1 = negative and positive, 2 = positive response $2^{nd}$ part: Code -9 for missing; Code themes (can be coded under multiple themes):

- Sensitive issue/willingness to discuss
  - Yes, if it applies to particular client and they are willing to discuss
  - Personal comfort
  - Clients unwilling to discuss
  - Client's reluctance
- Custody issues lost contact with children, afraid to discuss parenting due to custody concerns
  - The consumer's lack of wanting to discuss parenting
  - Discussion often leads to clients feeling threatened that their children might get taken ways from them
  - Concern that what they say will be used against them in the child welfare cases
  - A lot of our clients have lost their children CPS
- Poor parenting
  - Lack insight about being a parent/Lack of insight into mental illness
  - Client lack of knowledge and insight
  - Sometimes the client doesn't have the mental capacity to understand parenting
  - Lack of parenting skills/bad behaviors
  - Have mental illness, substance abuse, etc.
  - Most are too sick to adequately care for their children
  - Many have poor history with family
- Stigma/guilt of parents with mental illness
  - Family court stigma of mentally ill.
  - Lots of times members have a lot of shame regarding custody status and their past behaviors that affected their custody status
  - They've been told they are incapable.
  - Their own shame and guilt
- Lack of resources/stress
  - Poverty/no financial support

- Stress/ busyness/no time to parent
- Staff/Treatment Barriers
  - Not part of program or treatment/treatment not available
  - That we are here to serve the clients, the child/family is not the client
  - My training has been with adults primarily
  - Stuff not trained to work with people on these issues
- Other
- 9. How do you think parenting affects mental health and illness?

## $1^{st}$ part: Code 0 = negative, 1 = negative and positive, 2 = positive response $2^{nd}$ part: Code -9 for missing; Code themes (can be coded under multiple themes):

- Can be positive (general positive answers with little explanation)
- Source of motivation/recovery oriented
- Increases parent problems increases symptoms, makes mental illness worse
- Increases Responsibility
- Causes problems for children
- Additional source of stress more challenges or burdens.
- Stigma/feel guilty
- Lack of resources/finances
- Other
- 10. How do you think mental illness affects people's ability to parent?

## $1^{st}$ part: Code 0 = negative, 1 = negative and positive, 2 = positive response $2^{nd}$ part: Code -9 for missing; Code themes (can be coded under multiple themes):

- Can be positive/good parent
- Depends on person or situation/consumer characteristics Examples:
  - Depends on motivation and dedication as with any parent without a mental illness
  - Depends on the severity of the illness
  - Depends on their situation, past history and example of parenting
  - It depends how they internalize their illness and if they have a resilient
- Source of Motivation/recovery related
  - In some ways it can assist a consumer to want to stay healthy in order to take care of children
  - It can be a major focus point for motivating client toward recovery
- Parent problems skills deficit, mental illness symptoms

- Not effective, lack ability, no skills (general lack of skills but no specific skill/deficit identified)
- Bad behavior, do not adhere to meds or treatment, poor impulse control
- Poor emotional availability/flat affect, lack of empathy
- Poor thinking, judgment, organizational skills
- Causes problems for children
  - Problems with bonding, challenges to appropriately bond with infant child
  - Emotional problems in children, feelings of abandonment and fear in children
  - Developmental or cognitive problems in children, significant delays in the normal development process, and significant functional impairment
  - Poor care/treatment for children, cannot raise healthy children, less present and less able to respond to child's needs
  - Lack of structure, discipline, difficult for children to take parents seriously
- Source of stress additional challenges, barriers, burdens
  - Increased stress, increased symptoms due to stress
  - Limited ability to cope with stressors, decreased coping resources
  - Added stress could lead to increase in symptoms
  - I feel the stress of parenting can trigger increased anxiety and depression
- Stigma/feel guilty
  - Regret over loss of children
  - My patients' feel guilty about their illness, allow their child (in certain instances) to take advantage
  - Concerns that their child with inherit illness
- Lack of resources/finances
  - Poor housing conditions, unstable living situation
  - Medical care/medications
  - Daycare/custody issues
- Other
- 11. What do you think are the positive aspects of addressing parenting issues with consumers?

## Code -9 for missing; Code themes (can be coded under multiple themes):

- Helps consumers feel Better improves self-worth and self-esteem
  - It helps them feel more whole and real rather than an incomplete, disabled person
  - Builds self-esteem, they feel more confident and satisfied
  - Support them to empower them
  - Increased happiness with life
  - Generate hope to help families
- Improves relationship with children or family expand social support
  - Improves relationships with children

- Increased relationship building/engagement
- Improves emotional bond
- Enables parents to achieve success in parenting
- Learn, enhance, or practice tools and skills to be parent (psychoeducation)
  - It helps them to gain skills and strategies in being better parents
  - Allows them to use tool development and coping skills to become the teacher
  - They are provided with information and resources to make decisions that are necessary
  - Learn more effective ways to cope with parenting issues
- Improves therapeutic alliances between providers and consumers offers communication and support for consumers
  - Strengthens the therapeutic alliance by providing support
  - The consumer will have someone to confide in about parenting questions
  - Helps consumers with verbalizing thoughts, and feelings regarding issues and stressors
  - Allows them to openly address important and painful issues
- Reduces stress
  - Lessens anxiety and stress
  - Assists them dealing with stress and situations that present which exacerbate symptoms
- Safety
  - Health safety
  - Fostering a safer living environment
- Support
  - Need additional support
- Other

## Code 0 for no; Code 1 for yes:

12.	Does your team provide	e special programs	s/services designe	d for parents? (yes/no)
12.a	. If yes, briefly describe	e such programs:		

## Code 0 for no answer; Code -9 for missing (did not answer question 12); Code answers according to themes:

- Psychoeducation classes FSE (Family Services Education), FPE (Family Psycho Education)
- Family therapy/counseling family relationship sessions, parent and child interactive therapy
- Group classes peer support classes for families
- Make referrals
- Individual therapy one on one's with therapist, custom treatment planning
- Plan to get program or desire to get program
- Other (answers that do not fit above themes)

13. Does your team help consumers with a	ny of the following parent-related needs?
(Please check all that apply)	
Code 0 for no checked box; Code 1 for ch	necked box:
Day care/babysitter	Court appointments/custody issues
Food for children	Housing for children
Medical needs of children	Clothing/toys/personal items for children
Transportation/car seats for children	Helping children with schoolwork
Disciplining children	Communicating/interacting with children
13.a. Other:	communicating intoracting with ciniaren
	g (no boxes checked for question 13); Code
answers according to themes:	g (no boxes checked for question 13), Code
- CPS - department of children and fa	mily/other departments
•	•
- Client characteristics - not relevant	to current chents
- Team characteristics - team is new	
- Other - try recovery skills	
For #14-15 - Code as answers given; Code Know; Code -7 for Not applicable; Code 14. How many of your consumers are pare adopted, or foster)?  How many of these parents are female How many consumers are you unsur-	nts/caretakers of children (biological, step, ale?
15. How many consumers (those with and How many consumers are you unsur	· · · · · · · · · · · · · · · · · · ·
16. Please check your role on the team:	
Code 0 for no checked box; Code 1 for ch	
Psychiatrist	Nurse Practitioner
Psychologist	Social Worker
Substance Abuse Therapist	Occupational Therapist
Registered Nurse	Licensed Practical Nurse
Case Manager	Consumer/Peer Provider
16.a. Other (please describe):	
Code 0 for no answer; Code -9 for missin	g (no boxes checked for role); Code
answers according to themes:	
- Director/supervisor/administrator/m	anager
- Mental health professional/LPCC/L	PC/counselor
- Housing specialist	
- Paraprofessional	
- Court/criminal specialist	
17. Please check any of the following degree	ees vou have earned:
Code 0 for no checked box; Code 1 for ch	
MD (Psychiatry)	MD (Non-Psychiatry)

PhD (Psychology)	Ph.D. (Non-Psychology)
Psy D	□NP
□RN	LPN
Masters (Psychology)	Masters (Non-Psychology)
Bachelors (Psychology)	☐ Bachelors (Non-Psychology)
17.a. Other (please describe):	
	Code -9 for missing (no boxes checked for
question 17); Code themes (coded under o	only one theme):
- Peer certification	
- Alcohol and drug certification	
- Gambling addiction certification	
Code 0 for no; Code 1 for yes:	. 1.1
18. Are you the team leader of the ACT tea	
18.a. If not the team leader, please in	dicate profession of team leader:
Code as exact answer given; Code -9 for M	Missing .
19. How many staff members are on the tea	C
17. How many start members are on the tea	m:
20 Please check the type of city in which th	ne team serves (Please check only ONE box):
, i	e 3 for Urban small city; Code 4 for Urban
· · · · · · · · · · · · · · · · · · ·	or Other or more than one answer; Code -
9 for Missing	,
Rural (population less than 2,500)	
Mixed (rural and urban)	
Urban (small city with population less that	an 50,000)
Urban (large city with population more that	nan 50,000)
Suburban (within 20-30 miles of a city)	
20.a. Other (please describe):	
21. State in which ACT team serves:	
See SPSS for coding scheme of 50 states;	Code -9 for Missing

## Appendix C. Consumer Interview

ID:	Consumer DOB:	Consumer Age:	<b>Gender:</b> M	F
Clie	ent Ethnicity:	Consumer Race:		
		American Indian/Alaska Native:		
Non-	anic: -Hispanic:	Native American/Other Pacific Is		
Unkı	nown/not reported:	Asian:		
	• ———	Black or African American:		
		White:		
		More than one race:		
		Unknown or not reported:		
1. W	What is your marital status? (Circle on	ne)		
1.	Single	4. Divorced		
	Relationship (not married)	5. Widowed		
3.	Married	6. Other:		
	What is your highest level of education			
	No HS or GED	5. Associates degree		
	HS Diploma or GED	6. BA/BS		
	Vocational training certificate	7. Masters/PhD.		
4.	Some College	8. Other:		
3. W	What is your current educational stat	us? (Circle one)		
	N/A	<b>6.</b> Basic educational skills		
1.	No educational participation	7. Attending vocational school,	vocational	
	Vocational/Educational involvement	program, apprenticeship, or h		
	Pre-educational explorations	<b>8.</b> Attending college: <u>1-6</u> hours	8	
	*	9. Attending college: 7 or more	hours	
	Working on GED	10. Other (specify):		
5.	Working on English as second language	10. Other (speerly).	<del></del>	
4. C	onsumer Primary Diagnosis? (Circle	one)		
	Schizophrenia	4. Bipolar		
	. Schizoaffective	5. Depression		
	Personality Disorder/Axis II Disorder			
	a. Age at onset of diagnosis:			
	5 6 ······ <u></u>			
5. A	ge of first hospitalization:			
	a. Date of most recent hospitaliza	tion:		
	b. Total number of hospitalization			

5. Lives with relatives (but is largely independent) 6. Group home 7. Boarding house 8. Supervised apartment program lays), how many times are a lays and tric reasons? ce abuse reasons?	10 11 12	. Home. Emer. Other	gency Shelter (specify):	er 
6. Group home 7. Boarding house 8. Supervised apartment program lays), how many times are a stric reasons? ce abuse reasons?	11 12 	. Emerge. Other	gency Shelter (specify):  ou been:	
7. Boarding house 8. Supervised apartment program lays), how many times are arricreasons? ce abuse reasons?	12 — nd <u>days</u>	have y	r (specify): ou been:	
8. Supervised apartment program lays), how many times are attric reasons?	nd <u>days</u>	have y	ou been:	ents
program  lays), how many times are arric reasons?  ce abuse reasons?	nd <u>days</u>	have y	ou been:	ents
lays), how many times are tric reasons?		-		ents
tric reasons? ce abuse reasons?		-		ents
ce abuse reasons?				
ce abuse reasons?				
ce abuse reasons?				
ce abuse reasons?		<del></del>		
•				
ent status?				
5. Part-time Employment:				
5. Full-time Employment:				
7. Other:				
and vall receiving from	ACT?	Circle	all that app	lv)
s are you receiving from	,			~ ) /
Housing Services		Transpor	tation	-
	10. 7	•	rtation obation/Parc	
. Housing Services	10. T	Legal/Pr		ole
Housing Services Employment Services	10. T 11. I 12. I	Legal/Pr Payeeshi	obation/Parc ip/guardiansl	ole hips
<ul><li>Housing Services</li><li>Employment Services</li><li>Substance Abuse</li></ul>	10. 7 11. 1 12. 1 13. 0	Legal/Pr Payeeshi Clothing	obation/Parc	ole hips ood
	o. Full-time Employment:  orange of the control of the con	eiving ACT services?  en on an ACT team since this de	eiving ACT services?en on an ACT team since this date?	eiving ACT services?en on an ACT team since this date? Yes

Child	Age	Ger	nder (M or F	) Re	elatio	nship to participant (biological, step, adopted)
14. Do yo with? Child	u current Lives w	ith	e with any o Residence Child			dren? Who else do your children live ther people who live with child (other parent, grandparents, aunts, etc)
	(Y/N)					
15. Besid	es childre	n, wit	th whom do	you liv	/e?	(Circle all that apply)
1. Alone		.1 1		Paren		
	arent of chi ant other/p			Grand	•	
4. Roomm		artiici				ily members:
	helter/hous	_	sidents			
6. Friends	:		1	1. Other	:	
		what	are your ca	regive		ponsibilities?
<b>C</b>	hild				R	esponsibilities
17. How a		•	ou spend ca f activities d	_		ch child? ith each child?
Child	1,1200 03	_	Time Spent	20 J 002		Activities
	1					

Child	Someone helps care for	Person who helps care for child (other	How others help care for children
	child (Y/N)	parent, grandparent)	
9. Do	you have custody of	vour children?	
,,,,,,	Legal Custody	Physical Custody	
Child	Code as:	Code as:	<b>Custody Arrangement</b>
	<ol> <li>Full/Sole Legal</li> <li>Joint Legal</li> </ol>	<ul><li>3.) Full/Sole Physical</li><li>4.) Joint Physical</li></ul>	(weekends, once a week, etc.)
	2.) Joint Legar	4.) Joint I hysical	
20. Wh	at have been your e	xperiences with custod	y issues?
		xperiences with custod	
21. Wh	at are the positive p		ng a parent?
21. Wh	at are the positive p	arts or benefits of bein	ng a parent?

25.	How does being	a parent impact your abil	ity to follow/adhere to treatment?	_ _ _
26	What are your	needs as a parent?		_
	What are some	parent-related things you	would like help with from ACT	_
	Financial	<b>5.</b> Communication Skills	<b>10.</b> Activities for Children	
	Legal/Custody	<b>6.</b> Bonding with children	11. Helping with school	
3.	Resources (food, clothing, etc.)	7. Discipline	12. Transportation	
4.	Housing Housing	<ul><li>8. Social Skills</li><li>9. Social Support from Others</li></ul>	13. Other:	
	a. Does the A Why or why	CT team help you meet th	ese needs? Yes Sometimes	No
28.	How often? In what settin			_ N -
	much provide	CID		-
	Do you feel welc	_	a parent with ACT providers?	
<b>29</b> .		etimes No	Why or why not?	

	leel ACI	providers are con	niortable wi	hen talking	to you about being a
parent?	Yes	Sometimes	S	No	Why or why not?
		tally unsatisfied)			how happy are you ting?
Totally dissa	atisfied	Dissatisfied	Unsure	Satisfied	Totally Satisfied
1		2	3	4	5
32. Do vou l	have anv s	suggestions for th	nings that A	CT could de	o to help you as a
-			<b>g</b>		J ou and a
parent?					
parent?					
		rtable making su		•	-
33. Do you 1	feel comfo	_		your ACT Why or why	-
33. Do you 1		_		•	-
33. Do you 1		_		•	-
garent?  33. Do you f		_		•	-

## Appendix D. Consumer Interview Codebook

Enter as exact number; for gender $0 = \text{male}$ , $1 = \text{female}$					
ID: Consumer DOB:	Consumer Age: Gender: M F				
Code as 0=no and 1=yes; -9=missing/ur					
Client Ethnicity:	Consumer Race:				
Hispanic:	American Indian/Alaska Native:				
Non-Hispanic:	Native American/Other Pacific Islander:				
Unknown/not reported:	Asian:				
1	Black or African American:				
	White:				
	More than one race:				
	Unknown or not reported:				
1. What is your marital status? (Circle one	1				
For each marital status, code as 0=no a					
1. Single	4. Divorced				
2. Relationship (not married)	5. Widowed				
3. Married	6. Other:				
2. What is your highest level of education Code as specific number, -9=missing/ur					
1. No HS or GED	5. Associates degree				
2. HS Diploma or GED	6. BA/BS				
3. Vocational training certificate	7. Masters/Ph.D.				
4. Some College	8. Other:				
2 777	0.75				
3. What is your current educational status					
Code as specific number, $-9 = missing/v$					
Note: If other: code as $0 = no$ other, $1 = 0$					
<b>0.</b> N/A	<b>6.</b> Basic educational skills				
1. No educational participation	7. Attending vocational school, vocational				
2. Vocational/Educational involvement	program, apprenticeship, or high school				
3. No educational participation, but pre-	<b>8.</b> Attending college: <u>1-6</u> hours				
educational explorations	<b>9.</b> Attending college: 7 or more hours				
4. Working on GED	10. Other (specify):				
5. Working on English as second					
language					
language					
1. C D: 10/2: 1					
4. Consumer Primary Diagnosis? (Circle					
For each diagnosis, code as $0 = no$ , $1 = no$					
1. Schizophrenia	4. Bipolar				
<ul><li>2. Schizoaffective</li><li>3. Personality Disorder/Axis II Disorder</li></ul>	5. Depression 6. Other:				
a. Age at onset of diagnosis:	v. ouici.				
a. Age at onset of diagnosis.	<del></del>				

5. Age of first hospitalization a. Most recent hospitalization) b. Total number of	on: italization:	(Enter number o	f months since
6. What is your current live  After code for living arra  = missing  1. Psychiatric hospital  2. Nursing home  3. Family care home  4. Lives with relatives (heavily dependent for personal care)		ut 9. Indeper 10. Home	s 0 = no, 1 = yes, -9  ident Living less gency Shelter
15. Besides children, with For each type of person, of 1. Alone 2. Other parent of child 3. Significant other/partner 4. Roommate 5. Other shelter/housing resident.	code as $0 = \text{no}, 1 = \text{yes}, -\frac{1}{2}$ 6. Parents 7. Siblings 8. Multiple fami dents 9. Children:  ys), how many times and	9 = missing  ly members:  days have you b	
Code -9 for missing, Code Been homeless?	e exact number	# days	# incidents
Been incarcerated?			
Been hospitalized for psychia	atric reasons?		
Been hospitalized for substar			
7. What is your employm Code -9 for missing, Code	ent status?		
<ul><li>2. Volunteer</li><li>3. Disability/Benefits</li></ul>	<ul><li>5. Part-time Employment:</li><li>6. Part-time Employment a</li><li>7. Full-time Employment:</li><li>8. Other:</li></ul>	and collecting bene	
9. When did you start receiva. Have you always become date as number of i	en on an ACT team since		Yes No yes, -9 = missing

10. What types of services are you currently receiving from ACT? (Circle all that apply) For each type of service, code as 0 = no, 1 = yes, -9 = missing

1. Therapy/Counseling	5. Housing Services	10. Transportation
2. Case Management	6. Employment Services	11. Legal/Probation/Parole
3. Medication Management	7. Substance Abuse Services	12. Payeeship/Guardianship
4. Family Services	8. Education Services	13. Clothing/Furniture/Food
	9. Social Skills	14. Other

11. Are your receiving treatment services outside of ACT? If yes, what services?

Yes

No

Code 0=no, 1=yes, -9=missing/unclear;

Code answer as 0 = No provider outside ACT team, 1 = Medical Doctor, 2 = psychiatrist outside ACT team, <math>3 = other, -9 = missing

12. How many children do you have? \_\_\_\_\_ How many grandchildren do you have? \_\_\_\_\_ Code -9 for missing, Code exact number

13. How old are they? Are they female or male? What is your relationship to child? **Code age as exact number;** 

Code gender as 0 = male, 1 = female, -9 = missing/unclearCode biological as 0 = not biological, 1 = biological, -9 = missing, -8 = not applicable/no child

Note: If no additional children or grandchildren, code -8

14. Do you currently live with any of your children?

First Code each child: 0 = no, 1 = yes, -9 = missing/unclear, -8 = no child, -7 = deceased

Second Code: Is child an adult? 0 = no, 1 = no, never lived with adult child, 2 = yes, used to live with child, -9 = missing/unclear, -8 = no child, -7 = deceased

15. Who else do your children live with? – Residence of Children?

Code for each child: 1 = with participant, 2 = siblings of child, 3 = adoptive/foster family, 4 = other parent, 5 = family member (on participant's side), 6 = family member (other parent's family), 7 = child is adult/lives on own, 8 = child is adult/lives with own family, 9 = do not know, -9 = missing, -8 = not applicable/no child, -7 = deceased

Code for each grandchild: 1 = with participant, 2 = siblings of child, 3 = adoptive/foster family, 4 = with parent (participant's child), 5 = with other parent (NOT participant's child), 6 = family member (participant's side), 7 = family member (NOT participant's child), 8 = do not know, -9 = missing, -8 = not applicable/no grandchild, -7 = deceased

16. For your children (and grandchildren), what are your caregiver responsibilities?

For according to themes: 0 = no, 1 = yes, -9 = missing/unclear Caregiver Themes (can be coded under more than one theme):

- None
- Full Custody
- Children are Independent Adults
- Phone or Physical Visits
- Babysitting
- Financial Assistance
- Food
- Clothing/Items/Gifts
- Housing
- Give advice
- Other (e.g. wants to, but doesn't)

Note: For each theme, code 0 = no, 1 = yes, 2 = children are adults, but used to provide, -9 = missing. -8 = no child/grandchild

17. How much time do you spend caring for your children (and grandchildren)? Time spent with child: -9 = missing, -8 = no child, -7 = deceased, 0 = no time at all, 1 = contact via phone/letter/no physical contact, 2 = contact about once a year (or fewer), 3 = several times a year (3-6 times a year), 4 = about once a month, 5 = several times a month (2-3), 6 = at least once a week, 7 = several times each week, 8 = everyday/has custody, 9 = other

Note: If no grandchildren, code -8 for all variables

17.a. What types of activities do you do with your children (and grandchild)? For each theme, code 0 = no, 1 = yes, -9 = missing

Activity Themes (can be coded under more than one theme):

- Nothing/no custody
- Hang out/talk
- Eat/cook/restaurants
- Games/crafts
- TV/movies
- Hobbies of child
- Shop/gifts
- Outdoor activities
- Outdoor locations park, zoo
- Other

Note: If no grandchildren, code -8 for all variables

18. Does anyone help you care for your children?

Code: 0 = no, 1 = ves, -9 = missing, 2 = children are adults, but had help

### 18.a. Who are these people?

## Code according to themes: 0 = no, 1 = yes, -9 = missing

## People who help care themes (can be coded under more than one theme):

- Are adults, and had help caring for them as children
- Other Parent
- Participant's parents
- Other parent's parents
- Foster/adoptive family
- Participant's family
- Other parent's family
- Friend/neighbor of participant
- Other

### 18.b. How do they help?

### Code according to themes: 0 = no, 1 = yes, -9 = missing

## How people help themes (can be coded under more than one theme):

- Full responsibility (like adoptive parents)
- Financial
- Housing
- Food
- Toys/items/gifts
- Babysitting
- Transportation
- Games/activities
- Offer advice
- Other (e.g. religious education)

#### 19. Do you have custody of your children?

Code for each child: 0 = no custody/adopted, 1 = no custody/no contact, 2 = no custody/minimal contact, 3 = partial custody/custody arrangement, 4 = full custody, 5 = adult child/had custody as child, 6 = adult child/did not have custody as child, -9 = missing/unclear, -8 = no child, -7 = deceased

#### 19.a. Did you ever lose custody?

Code for each child: 0 = never lost custody/retained full custody, 1 = lost full custody/retained partial custody, 2 = lost custody – got it back; 3 = lost custody – permanently, 4 = never had custody/gave up for adoption, 5=other, -9 = missing/unclear, -8 = no child, -7 = deceased

#### 19.b. What is your custody arrangement?

Code for each child: 0 = never had custody/adopted, 1 = no arrangement/no contact, 2 = no arrangement/minimal contact (several times a year) 3 = no arrangement/occasional contact (about once a month), 4 = arrangement/occasional contact (about once a month), 5 = arrangement/frequent contact (at least every other week), 6 = full

## custody, 7 = child is adult/no contact at present, 8 = child is adult/contact at present; -9 = missing/unclear, -8 = no child, -7 = deceased

20. What have been your experiences with custody issues?

## For each theme, code 0 = no, 1 = yes, -9 = missing

## **Custody Themes (can be coded under more than one theme):**

- No answer/explanation
- N/A has maintained custody
- Never had custody gave up custody to adoptive/foster family
- Lost custody worked to get custody back, felt motivated
- Negative/Painful experience heartbreaking, traumatic, stressful
- Confusing experience not sure what to do, how to get them back
- Affected relationship with children seen as deadbeat
- Separation could not live with them, separation
- Legal problems involved court, jail, etc.
- Other

## 21. What are the positive parts or benefits of being a parent?

## For each theme, code 0 = no, 1 = yes, -9 = missing

### Benefits Themes (can be coded under more than one theme):

- Seeing children grow up
- Raising/Teaching children
- Love given and received
- Spending time with children hanging out, being with kids, etc.
- Relationship with children
- Spoiling/Giving Gifts
- Affect Children's Lives/Passing on Name
- Other

#### 22. What are the negative parts or challenges of being a parent?

## For each theme, code 0 = no, 1 = yes, -9 = missing

## Challenges Themes can be coded under more than one theme):

- No answer/no negative parts of being parent
- Separation not seeing and/or talking to children
- Punishments/discipline
- Responsibilities taking care of them, chores, laundry, etc.
- Resources and finances providing for children
- Getting along with rest of family, other parent
- Seeing child in pain
- Other

23. How does your mental illness impact your parenting?

## For each theme, code 0 = no, 1 = yes, -9 = missing

## Mental Illness Impacts Parenting Themes (can be coded under more than one theme):

- Don't know
- Medication side effects
- Mood/symptoms of mental illness
- Stress/worry
- Concern of children's view of participant
- Other substance abuse, memory

## 24. How does being a parent impact your mental health?

## For each theme, code 0 = no, 1 = yes, -9 = missing

## Parenting Impacts Mental Illness Themes (can be coded under more than one theme):

- Don't know or doesn't impact it
- Symptoms/Mood
- Difficulty handling stress adds stress and problems
- Impacts relationship with children
- Serves as motivation
- Other not relevant answer

### 25. How does being a parent impact your ability to follow/adhere to treatment?

## For each theme, code 0 = no, 1 = ves, -9 = missing

## Parent Impacts Treatment Themes (can be coded under more than one theme):

- Doesn't impact it OR don't need treatment
- Source of motivation
- Reason to seek counseling
- Other

## 26. What are your needs as a parent?

## For each theme, code 0 = no, 1 = ves, -9 = missing

## Needs as a Parent Themes (can be coded under more than one theme):

- No answer or don't know
- Never had custody, so no needs
- Don't need help
- Therapy family therapy, counseling to improve parenting, learning parenting skills, coping skills
- Custody Issues see children more often, assistance dealing with adoptive family
- Support emotional support, social support Resources and Finances personal items for children, gifts, etc.
- Communication with children bonding with children
- Other helping children with schoolwork

27. What are some parent-related things you would like help with from ACT members? For each thing, code 0 = no, 1 = yes, -9 = missing

1.	Financial	5.	Communication/Bonding	8. Activities for Children/Schoolwork
2.	Legal/Custody		with children	9. Transportation
3.	Resources	6.	Social Skills/education	10. Family Therapy/Counseling
	(food, clothing,		about mental illness	11. Other
	etc.)	7.	Social Support from	
4.	Housing		Others	

a. Does the ACT team help you meet these needs?

Yes Sometimes

No

Code 0=no, 1 = sometimes, 2 = yes, 3 = NA/no needs, -9 = missing Why or why not?

For each theme, code 0 = no, 1 = yes, -9 = missing

ACT team helps meet needs themes (can be coded under more than one theme):

- No answer/don't know
- Don't have needs
- Negative aspects of team too busy, don't have resources, won't listen
- Positive aspects of team help, provide services, caring providers
- Other

28. Do you talk about your children with your ACT providers? Yes Sometimes No Code 0 = no, 1 = yes, -9 = missing

28.a. How often?

Code: 0 = never discuss, 1 = occasionally, 2 = every other week, 3 = at least weekly, 4 = all the time, -9 = missing/unclear

28.b. In what setting? \_\_\_\_\_

For each theme, code 0 = no, 1 = yes, -9 = missing Setting themes:

- No setting/doesn't talk about children
- Therapy session
- During informal conversation
- During transport/car
- During drop-ins/house visits
- Other

28.c. Which providers? \_\_\_

For each theme, 0 = no, 1 = yes, -9 = missing

### **Provider themes:**

- No providers
- All providers
- Therapist
- Case manager
- Team Leader
- Peer Specialist

- Nurse/Psychiatrist		
- Other (e.g. transportation person)		
29. Do you feel welcomed to talk about being a parent with ACT providers?		
Yes Sometimes No		
Code $0 = \text{no}$ , $1 = \text{yes}$ , $-9 = \text{missing}$		
Why or why not?		
For each theme, code $0 = \text{no}$ , $1 = \text{yes}$ , $-9 = \text{missing}$		
Talk with ACT providers Themes:		
- No answer/don't know		
- Positive aspects of team - listens well, supports participant, asks about children		
- Negative aspects of team - team doesn't treat children		
- Depends on provider - comfortable with some providers but not others		
- Other - no interest in talking about children		
20. Do you feel ACT providers are comfortable when telling you shout being a result?		
30. Do you feel ACT providers are comfortable when talking you about being a parent?  Yes Sometimes No		
Code $0 = \text{no}$ , $1 = \text{sometimes}$ , $2 = \text{yes}$ , $-9 = \text{missing}$		
Why or why not?		
See codes for previous question		
31. On a scale of 1 (totally unsatisfied) to 5 (totally satisfied), how happy are you with the amount of support from ACT team regarding parenting?  Totally dissatisfied Dissatisfied Unsure Satisfied Totally Satisfied  1 2 3 4 5  Code as exact number 1-5		
31.a. Can you explain to me why you said ?		
For each theme, code $0 = \text{no}$ , $1 = \text{yes}$ , $-9 = \text{missing}$		
Reasons for score Themes (can be coded under more than one theme):		
- No answer/don't know		
- Positive aspects of team - empathetic, makes good effort, offers adequate		
services		
- Negative aspects of team - limited resources, time, services		
- Depends on interpersonal relationships – depends on provider		
- Other		
32. Do you have any suggestions for things that ACT could do to help you as a parent?		
Yes Sometimes No		
Code as 0 = no suggestion, 1 = suggestion, -9 = missing		
Suggestion Themes (can be coded under more than one theme):		
- No answer/can't think of any		
- Satisfied with services, so no suggestions		

- General non parent-related improvements - listen better, be sympathetic, etc.

- Therapy-related improvements family therapy, involve children in therapy, provide parenting advice in treatment
- Parent-related improvements better communication with children, activities to do with children, transportation to see children
- Other financial help
- 33. Do you feel comfortable making suggestions to your ACT providers?

Yes Sometimes No

Code 0 = no, 1 = sometimes, 2 = ves, -9 = missing

33.a. Why or why not?

For each theme, code 0 = no, 1 = yes, -9 = missing Reasons for score Themes:

- No answer/don't know
- Positive aspects of team or let team control treatment
- Yes, because participant has made suggestions in past
- Yes, because of good communication skills outspoken, able to share opinion
- Other why make suggestions?
- 34. What is your favorite memory of being a parent?

For each theme, code 0 = no, 1 = yes, -9 = missing Memory Themes:

- Not asked this question
- Giving birth or witnessing milestones
- Loving children cuddling, hugging
- Holidays celebrations, baptism, birthdays
- Buying gifts and spoiling children
- Outdoor activities swimming, camping, horseback riding

# Appendix E. Informed Consent Document

# INDIANA UNIVERSITY INFORMED CONSENT STATEMENT FOR Parents Served by Assertive Community Treatment: A Needs Based Assessment

You are invited to participate in a research study assessing the needs of parents served by Assertive Community Treatment (ACT). You were selected as a possible subject because you are a parent with a severe mental illness currently being served by an ACT team. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

The study is being conducted by Dr. John McGrew, Director of the Clinical Psychology Department, Indiana University-Purdue University, Indianapolis, and Laura White, a Clinical Psychology Doctoral Student, at Indiana University-Purdue University, Indianapolis. The study is partially funded by the National Institute of Mental Health, under the Recovery Oriented ACT Grant.

# STUDY PURPOSE

The purpose of this study is to gather information about the practices, attitudes, beliefs, benefits, challenges, and needs of parent consumers served by ACT teams. Such information will be used to determine whether the ACT treatment approach adequately helps and supports parent consumers.

# NUMBER OF PEOPLE TAKING PART IN THE STUDY:

If you agree to participate, you will be one of 20 subjects who will be participating in this research.

# PROCEDURES FOR THE STUDY:

If you agree to be in the study, you will do the following things:

- Read and sign this informed consent statement
- Participate in one interview consisting of approximately 35 questions about your background, mental illness, children, experiences with custody issues, parenting attitudes and beliefs, feelings about ACT services, and suggestions for ways to improve ACT services
- Possibly participate in a follow-up interview that will take place up to two months after the initial interview to provide clarification and/or elaboration on initial interview responses
- Allow researchers to audiotape the interview(s)

All participants will be asked the same general interview questions individually in a single session, located in a safe and private room. The total amount of time needed to complete the interview is approximately 1-2 hours, depending on the length your interview responses. The follow-up interview is expected to last about 30 minutes and not all of you will be asked to participate in a follow-up interview.

# RISKS OF TAKING PART IN THE STUDY:

As a participant in the study, the risks of completing the interview include possible discomfort answering personal questions, loss of confidentiality, and potential legal consequences for reporting child abuse. The likelihood of these risks are minimal, since you have the right to refuse to answer any question(s) that are distressing and you have the right to end the interview early, without penalty or punishment. You also have the right to deny the research team permission to write down and/or audiotape your responses during the interview. You may also ask the research team to stop writing and/or audio taping your responses at any point during the interview. Furthermore, numerous efforts (outlined below in the confidentiality section) will be made to keep all your information protected and confidential. However, the confidentiality of your responses may be broken if you report any form of sexual and/or physical child abuse, such as witnessing a child being forced to engage in sexual activity against his/her will. Instances of child abuse will be reported to the authorities and you may face legal consequences for your role in the abuse. If you feel any interview question(s) may require a response that will get you into legal trouble, you have the right not to answer the questions(s).

# BENEFITS OF TAKING PART IN THE STUDY:

The benefits you can reasonable expect from participating in the study include the opportunity to share your thoughts, attitudes, and experiences of being a parent with a severe mental illness. You will also be able to make suggestions and recommendations to improve ACT treatment teams. By participating in the interview, you are contributing to research aimed at better understanding the needs of parents with mental illness and helping researchers improve treatment services, like ACT, so that these treatments can better serve and support parent consumers.

# ALTERNATIVES TO TAKING PART IN THE STUDY:

You do not have to participate in the research. If you decide to take part in the research it should be because you want to volunteer. There is no alternative to taking part in the study, so choosing not to volunteer means no involvement in the study. You will not lose any rights or benefits you would normally have if you choose not to volunteer. You can stop at any time during the studies and still keep the benefits and rights you had before volunteering.

# **CONFIDENTIALITY**

Efforts will be made to keep your personal information confidential. For example, your name will be kept separate from the information collected during the study. These two things will be stored in different places under lock and key, so your identity will not be linked to your interview responses. The tape recordings of your interview will also be kept under lock and key, with only the research team having access to the tapes. These audiotapes will be securely filed for up to five years, with the possibility of using the tapes for future research. During this time, they will only be accessible to the research team and permanently destroyed at the end of time frame. Also, your information will be combined with information from other people taking part in the research. When we write up the study to share with other researchers, we will write about this combined information. You will not be identified in these published materials or in databases in which results may be stored.

However, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law. As previously discussed, the law requires any mention of child abuse be reported to the authorities. Further, organizations that may inspect and/or copy your

research records for quality assurance and data analysis include groups such as the study investigator and his/her research associates, the Institutional Review Board or its designees, and state or federal agencies, specifically the Office for Human Research Protections (OHRP) and the National Institutes of Health (NIH).

# COSTS/PAYMENT

There are no costs associated with taking part in this research. Instead, you will receive payment in the form of a \$25 gift card for Target, Wal-Mart, or March grocery store for taking part in this study. If you should have to quit before the study is finished, you will still be able to keep the gift card.

# CONTACTS FOR QUESTIONS OR PROBLEMS

Before you decide whether to accept this invitation to take part in the research, please ask any questions that might come to mind now. Later, if you have questions about the study or a research-related injury, contact the researcher, Dr. John McGrew, Director of Clinical Psychology Program, at (317) 274-8672 or <a href="mailto:jmcgrew@iupui.edu">jmcgrew@iupui.edu</a>. You may also contact Laura White at (317) 278-2516 or <a href="mailto:jmcgrew@iupui.edu">jmcgrew@iupui.edu</a>.

For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IU Human Subjects Office at (317) 278-3458 or 800-696-2949 or by email at iub\_hsc@indiana.edu

### **VOLUNTARY NATURE OF STUDY**

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled.

# SUBJECT'S CONSENT

In consideration of all of the above, I give my consent to participate in this research study.

I will be given a copy of this informed consent document to keep for my records. I agree to take part in this study.

Subject's Printed Name:	
Subject's Signature:	Date:
Printed Name of Person Obtaining Consent:	
Signature of Person Obtaining Consent	Date <sup>.</sup>

# Appendix D. Debriefing Form

Thank you for your participation in the present study concerning parents served by Assertive Community Treatment (ACT). In this study, we asked you a number of questions about your background, mental illness, children, parenting experiences, parenting needs, and treatment suggestions. It is difficult to answer these types of questions, and your generosity and willingness to participate in this study are greatly appreciated. Your input will help contribute to advancements in the field of parenting, severe mental illness, and psychiatric interventions, as well as help researchers better understand the thoughts, beliefs, attitudes, needs, and experiences of parents served by ACT teams.

Again, we thank you for your participation in this study. If you know any friends or acquaintances that may be eligible to participate in this study, we ask that you inform them about the study and give them our contact information. However, you are not required to do so. Please do not discuss the interview questions with others until after they have had the opportunity to participate. Prior knowledge of questions asked during the study can invalidate the results. We greatly appreciate your cooperation.

If you have any questions regarding this study, please feel free to ask the researcher at this time. If you have any questions or concerns in the future, please feel free to contact Laura White at 317-278-2516 or <a href="mailto:laumwhit@iupui.edu">laumwhit@iupui.edu</a> or contact Dr. John McGrew at 317-274-8672 or <a href="mailto:jmcgrew@iupui.edu">jmcgrew@iupui.edu</a>. You may also contact these individuals via mail at Indiana University-Purdue University Indianapolis, Department of Psychology, 402 Blackford Street, LD 126, Indianapolis, IN, 46202.

If you are interested in this area of research and would like to learn more about it, you may wish to read the following articles:

- Boursnell, M. (2007). The silent parent: Developing knowledge about the experiences of parents with mental illness. *Child Care in Practice*, *13*(3), 251-260.
- Nicholson, J., Hinden, B., Biebel, K., Henry, A., & Katz-Leavy, J. (2007). A qualitative study of programs for parents with serious mental illness and their children: Building practice-based evidence. *Journal of Behavioral Health Services*, *34*(4), 395-413.

Nicholson, J., Sweeney, E. M., & Geller, J.L. (1998). Focus on women: Mothers with mental illness: The competing demands of parenting and living with mental illness. *Psychiatric Services* 49, 635-645.

Thank you very much for your participation and help with this research!



# VITA

# Laura Morgan White

Education		
2012	Master of Science, Clinical Psychology Indiana University-Purdue University Indianapolis, Indiana Advisors: John McGrew, PhD, and Michelle Salyers, PhD Thesis: Parents Served by Assertive Community Treatment: A Needs Based Assessment	
2008	Bachelor of Science, Psychology, Summa Cum Laude Loyola University Chicago, Illinois Advisor: R. Scott Tindale, PhD Independent Study: The Use of Reasoning in Resource Allocation Decisions	
2008	Bachelor of Arts, Communication, Summa Cum Laude Loyola University Chicago, Chicago, Illinois Advisor: Elizabeth Lozano, PhD Independent Study: Female Communication: A Qualitative Analysis of Communication Between Female College Senior Students and Female First Year Students	
Honors, Awards, and Fellowships		
2011-2012	Research Assistantship, Department of Psychology, Indiana University-Purdue University Indianapolis	
2010-2011	Research Assistantship, Department of Psychology, Indiana University-Purdue University Indianapolis	
2009-2010	Graduate Student Fellowship, Department of Psychology, Indiana University-Purdue University Indianapolis	
2009-2011	Dean's List, School of Science, Indiana University-Purdue University Indianapolis	
2008	Outstanding Achievement in Communication, Loyola University Chicago	

2006-2008 Presidential Scholarship, Loyola University Chicago

2004-2008 Dean's List, College of Arts and Sciences, Loyola University

Chicago

2006 Who's Who Among Students in American Colleges and

Universities

2004-2006 Damen Scholarship, Loyola University Chicago

Research Experience

2009-present Research Assistant and Head of Technical Assistance

ACT Center of Indiana, Indiana University-Purdue University

Indianapolis, Indiana

Advisors: John McGrew, PhD, and Michelle Salyers, PhD

2010-present Research Assistant

Roudebush Veteran's Administration Medical Center,

Indianapolis, Indiana

Advisors: Alan McGuire, PhD, and Michelle Salyers, PhD

2006-2008 Research Assistant

Department of Psychology, Loyola University Chicago, Illinois

Advisor: R. Scott Tindale, PhD

2008 Independent Mixed-Method Research Study

Department of Psychology, Loyola University Chicago, Illinois

Advisor: R. Scott Tindale, PhD

2007 Independent Qualitative Research Study

Department of Communication, Loyola University Chicago,

Illinois

Advisor: Elizabeth Lozano, PhD

Clinical Experience

8/2011-present **Psychology Student Intern** 

Beacon Psychology Services, Carmel, Indiana

Supervisor: Jennifer Horn, PhD, HSPP

2011 Psychology Student Intern

Larue D. Carter Memorial Hospital, Indianapolis, Indiana

Supervisors: John Spanke, PhD, HSPP, and Angela Neese, PhD

2010 **Psychology Student Intern** 

Roudebush Veteran's Administration Medical Center,

Indianapolis, Indiana

Supervisor: Paul Lysaker, PhD, HSPP

2010 Graduate Student Clinician

Indiana University-Purdue University Indianapolis, Indiana Supervisors: Alan McGuire, PhD and Michelle Salyers, PhD

2008-2009 Children's Counselor and Programming Coordinator

Catherine's Hearth Homeless Support Center, Baltimore, Maryland Mercy Volunteer Corps (AmeriCorps Program)

Supervisor: Dorothy Dobbyn, MSW

# **Assessments Administered**

- Adaptive Behavior Assessment System-2
- Attention Deficit Hyperactivity Disorder (ADHD) Screener
- Autism Diagnostic Observation Scale (ADOS)
- Beck Depression Inventory (BDI)
- Behavioral Assessment System for Children (BASC-2)
- Behavioral Assessment System -Children, Teacher and Parent Rating
- BLERT
- Brown Attention-Deficit Disorder Scales – Self, Teacher, and Parent Rating Scales
- California Verbal Learning Test 2
- Children's Depression Inventory II
- Hinting Task
- Kaufman Brief Intelligence Test 2
- Mental Status Examination
- Minnesota Multiphasic Personality Inventory (MMPI-II) and Adolescent (MMPI-A-II)
- NEO-Personality Inventory-Revised
- Oral and Written Language Scale
- Posttraumatic Stress Symptom Scale
- Rorschach Inkblot Test
- Rotter Incomplete Sentences Blank

- Sense of Self Inventory
- Social Language Development Test
- Stressful Life Experiences Screening Inventory
- Test of Everyday Attention for Children
- Test of Word Reading Efficiency
- Test of Written Language- 4
- Thematic Apperception Test (TAT)
- Vanderbilt ADHD Diagnostic Parent Rating and Teacher Rating Scales
- Wechsler Adult Intelligence Scale (WAIS-IV)
- Wechsler Individual Achievement Test -
- Wechsler Intelligence Scale for Children (WISC-IV)
- Wechsler Preschool and Primary Scale of Intelligence-III
- Wide Range Achievement Test (WRAT)
- Wisconsin Card Sorting Test
- Wide Range Assessment of Memory and Learning II
- Woodcock-Johnson III Tests of Achievement
- Woodcock-Johnson III Tests of Cognitive Abilities

**Teaching Experience** 

2009-2010 Teaching Assistant

Psychology 499, Honors Research Seminar

Department of Psychology, Indiana University-Purdue University

Indianapolis, Indiana

2008-2009 **Substitute Instructor** 

Psychology 104, Psychology as a Social Science

Department of Psychology, Indiana University-Purdue University

Indianapolis, Indiana

2004-2008 Private Tutor

Biology, Mathematics, Statistics

Schererville, Indiana

2005-2008 **Tutor** 

English, Spanish, Mathematics, Reading, Writing, Science, History

Inspired Youth Tutoring, Chicago, Illinois

2005-2007 Elementary School Substitute Teacher

Kindergarten - 4th grade

Merrillville Community School Corporation, Merrillville, Indiana

# **Professional Associations**

• Society for the Teaching of Psychology

- Psychology Graduate Student Organization, Treasurer 2010-present
- The American Psychological Association of Graduate Students
- National Society of Collegiate Scholars, Vice-President during 2007-2008
- Phi Beta Kappa National Honor Society, Oldest Honor Society in United States of America
- Golden Key, International Honor Society
- Alpha Sigma Nu, National Jesuit Honor Society
- Lambda Bi Eta, Beta Rho Chapter, National Honor Society in Communication

# Works in Progress

2011 Co-author, Reliability of the IMR treatment integrity scale (IT-IS):

Development and Reliability. *Psychiatric Services* (Under Review)

# Workshops and Conferences

10/2011 Overview of Mental Health and Behavioral Consultation

Presenter: Lisa Ruble, PhD, Associate Professor of Educational

Psychology, University of Kentucky

Location: Indiana University-Purdue University Indianapolis, Indiana

8/2011 **Sort & Sift, Think & Shift: Multidimensional Qualitative Analysis**Presenter: Raymond Maietta, PhD, Research Talk Inc.
Location: Indiana University-Purdue University Indianapolis, Indiana

# 7/2011 Review of Assertive Community Treatment Teams' Fidelity Co-presenter with John McGrew, PhD, Professor of Psychology, Indiana University-Purdue University Indianapolis; Angela Rollins, PhD, Assistant Research Professor, Indiana University-Purdue University Indianapolis Location: Department of Mental Health and Addictions, Indianapolis,

# 7/2011 Fidelity Assessment of Illness Management and Recovery

Presenters: Michelle Salyers, PhD, Professor of Psychology, Indiana University-Purdue University Indianapolis; Alan McGuire, PhD, Research Scientist, Roudebush Veteran's Administration Medical Center, Indianapolis, Indiana

Location: Richard L. Roudebush Veteran's Administration Medical Center, Indianapolis, Indiana

# 6/2011 Motivational Interviewing with Assertive Community Treatment

Presenters: Hea-Won Kim, PhD Associate Professor in the School of Social Work, Indiana University Indianapolis; Angela Rollins, PhD, Assistant Research Professor, Indiana University-Purdue University Indianapolis

Location: Indiana University-Purdue University Indianapolis, Indiana

# 3/2011 Group Schema Therapy Workshop

Indiana

Presenters: Joan Farrell, PhD, Adjunct Professor, Indiana University School of Medicine; Ida Shaw, MSW, Private Clinician Location: Indiana University-Purdue University Indianapolis, Indiana

# 1/2011 Introduction to Grounded Theory A Social Constructionist Approach Presenter: Kathy Charmaz, PhD, Sonoma State University, Research Talk Inc.

Location: Cary, North Carolina

# 6/2010 **26**<sup>th</sup> Annual Assertive Community Treatment Conference

Presenters: Members of Assertive Community Treatment Association Location: Hyatt Regency Hotel Conference Room, Chicago, Illinois

# 10/2009 Festschrift for Gary Bond

Presenters: John McGrew, PhD, Professor of Psychology, Indiana University-Purdue University Indianapolis; Angela Rollins, PhD, Assistant Research Professor, Indiana University-Purdue University

Indianapolis; Kim Mueser, PhD, Adjunct Professor of Psychiatry, Dartmouth Medical School; Gregory Teague, PhD, Associate Professor, University of South Florida; Charles Rapp, PhD, Research Professor, The University of Kentucky; and Anthony Zipple, MBA, Chief Executive Officer, Threshold Rehabilitation Industries

Location: Indiana University-Purdue University Indianapolis, Indiana

# 10/2008 Caring for our Children's Mental Health: Evidence Based Practices in Children's Mental Health Workshop

Presenters: Members of National Alliance on Mental Illness, Metropolitan

Baltimore Chapter

Location: Baltimore, Maryland

# 5/2008 Midwest Psychological Association Conference

Presenters: Members of the American Psychological Association

Location: Chicago, Illinois