Parent Support: Building Structures That Support and Assist Children

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June, 2007

This project was supported through a contract with the Kansas Department of Social and Rehabilitation Services Division of Health Care Policy - Mental Health Services
ACKNOWLEDGEMENTS

The authors would like to first thank families for sharing their experiences with us. We would also like to thank Parent Support Specialists for their dedication and commitment to family driven services. We would also like to thank the Community Mental Health Center Staff for their gracious assistance and patience during site visits.

Special thanks go to Pam McDiffett, Sherri Luthe and Mary McCoy for positive support and guidance throughout the study.

In addition we would like to thank all those community based staff who provided feedback on an initial draft of the study.

Last but not least, the University of Kansas School of Social Welfare Office of Child Welfare and Children’s Mental Health staff for diligent editing and assistance refining the report (see title page). Extra special thanks go to Heather Laskey, Susan Corrigan, Emily McCave and Kathy Byrnes.
EXECUTIVE SUMMARY

STUDY PURPOSE

Parent Support has been established as a promising practice by federal agencies such as the Substance Abuse Mental Health Services Administration, the Federation of Families, and the Research and Training Centers for Children's Mental Health (Ireys, Devet, & Sakwa, 2002). The state of Kansas is working to sustain the infrastructure of Parent Support Specialist (PSS) services within the mental health system of care. The goal of this study was to support this endeavor through an investigation of the components of effective PSS practices in Kansas. Parent Support Specialist services in the present study are provided by employees of the Kansas community mental health system. The large majority of PSS are parents or family members of children who experience a Serious Emotional Disturbance (SED) and as such bring a unique perspective to community mental health center (CMHC) treatment. Kansas has two funding sources for provision of PSS services: Home and Community Based Services (HCBS) Serious Emotional Disturbance (SED) Waiver and the Family Centered System of Care (FCSC) grant funding.

SERVICES PARENT SUPPORT SPECIALISTS PROVIDE

The following passage from the HCBS SED Waiver describes PSS services.

Parent Support is a service that provides the training and support necessary to ensure engagement and active participation of the family in the treatment planning process and with the ongoing implementation and reinforcement of skills learned throughout the treatment process. Training is provided to family members to increase their ability to provide a safe and supportive environment in the home and community for the consumer. This involves: 1) assisting the family in the acquisition of knowledge and skills necessary to understand and address the specific needs of the consumer in relation to their mental illness and treatment; 2) developing and enhancing the families specific problem-solving skills, coping mechanisms, and strategies for the consumer's symptom/behavior management; 3) assisting the family in understanding various requirements of the waiver process, such as the crisis plan and plan of care process; 4) training on the child’s medications or diagnoses; 5) interpreting choice offered by service providers; and 6) assisting with understanding policies, procedures and regulations that impact the consumer with mental illness while living in the community (Application for a 1915 (c) HCBS Waiver; Version 3.3 retrieved on June 7, 2007, from http://www.medicaidtraining.org/MedicaidTraining2.0/PDF/StatePlanTools/1915cSEDWaiverAmendment030107.pdf).
The children’s mental health literature describes effective family support programs as professional-parent partnerships developed through a family-driven approach. This approach encourages processes where goals are assessed in true partnership with families and are grounded in the experience, expertise, hopes, desires, and needs of the children and their families. Furthermore, this model emphasizes power sharing among professionals and participants. The services are developed using a family-driven framework, which means families are the primary decision makers in establishing a formal and informal array of services (Freisen & Huff, 1996).

The continuum of roles for families in their children’s care as primary decision makers has expanded from involvement to leadership. Family members are collaborating with professionals to function as advisers, service planners, providers, and evaluators (Osher & Osher, 2002).

One such role, parents as providers, is receiving increased attention due to the positive impact they have on child serving systems. Parent to parent support interventions facilitate collaborative relationships between families and service providers (Ireys, Devet, & Sakwa, 2002). In addition, existing studies indicate parent to parent support interventions impact family outcomes by improving parents’ ability to cope with family relations, and children’s behavior (Davis & Rushton, 1991; Davis & Spurr, 1998; Koroloff & Friesen, 1991). The mutual connections that are recognized in the initial interactions between parent to parent support providers and parents create a foundation on which a therapeutic relationship is built (Ireys, Devet, & Sakwa). With careful attention to the therapeutic value of self-disclosure, parent providers bring credibility to their work which reinforces the value of the relationship for parents. Parents gain hope when they understand how other parents were able to improve their parenting abilities.

METHODS

A mixed-methods approach was utilized which consisted of focus groups, interviews, and questionnaires as well as secondary data analysis of an existing database (Barfield, Corrigan, Chamberlain, Hong, & Barret, 2006). Stakeholders’ feedback and engagement were sought throughout the course of the study.

Data were collected at eight CMHCs. Sites were selected based on state recommendations of exemplary PSS programs and statewide geographic and population density representation. In addition, parents and PSS at other CMHCs completed questionnaires that were mailed to KU. A draft report was sent out to a representative group of PSS stakeholders for initial feedback, based on state recommendations. Then the draft reports were sent out to all
eight CMHCs as well as to all PSS for feedback. Follow-up phone calls were made and emails sent to all PSS and all 8 CMHC program administrators. In addition, two researchers conducted a focus group at a statewide PSS meeting. Feedback from stakeholders is included throughout the report.

**KEY FINDINGS**

1. **Children Whose Parents Receive Support Have Better Outcomes**
An analysis of data from a previous study (Barfield et al., 2006) indicates that children whose parents received PSS services have better outcomes in terms of residential status, law enforcement contact, academic performance, and school attendance. In addition, children whose parents were receiving PSS demonstrated fewer externalizing behaviors than children whose parents were not receiving support.

2. **Identification of Most Helpful Functions**
Parent support fulfill a wide range of roles and functions based on what is determined as needed in the individualized treatment planning process. However, the study identified 24 distinct roles and functions that PSS provide. Based on cumulative results, the most helpful functions PSS performed on treatment teams included the following: 1) emotional support, 2) peer support, 3) practical crisis coaching, 4) translating all perspectives on the treatment team, and 5) establishing goal-directed or purpose driven services.

3. **Services Are Beneficial to Parents and Children**
The majority (98%) of parents agreed that the PSS services they receive improve family functioning and child well-being. Furthermore, the majority (97%) of parents agreed that PSS services helped improve the conditions for which their children were receiving services at the CMHC. Interventions impact children’s environments by improving parenting abilities and increasing the efficiency of the community based services.

3.1 **Improvement in Parenting Abilities**
Parent Support Specialists provide emotional and peer support which gives parents hope.

> *When my kids were diagnosed I felt helpless & hopeless. Helps to know someone else went through this and made it to the other side. If a child could do better, he would. You know what? If a parent could do better, they would: They just get so beat down that they can’t get up sometimes. That’s what we do. We give them hope.*

*Parent Support Specialist*

Parent Support Specialists help parents understand their children’s mental health challenges and see their potential.
PSS help parents remember there are multiple strengths about their children and she doesn’t judge them by doing that. Parent support is educating parents about their children’s good traits.

Direct Service Staff

Parent Support Specialists teach parenting classes and provide individualized parenting consultation. These activities help parents gain confidence in their parenting abilities.

I’ve had 5 years of parent support. I’m very different than I was 5 years ago. I deal with my children differently. I handle them better. Without her, I would not be where I am. My children would not be where they are. My children are much better off because of parent support, even though parent support does not work directly with them. My children feel the effects of everything parent support teaches me.

Parent

Parent Support Specialists teach parents self care strategies. These strategies assist parents to be less reactive to the stress they experience as a result of parenting children with an SED.

Parent support can help give you the tools to stay more stress-free, calmer and think things through, so you can have a calmer environment.

Parent

Parent Support Specialist services empower parents to model the path to recovery for their children.

My child sees that I do get angry and upset. He’s seen that some of the ways of coping for him are also the way I cope. So he picks up some of my coping. There have been times when he’ll look at me and he goes “I’m going to my room”. Just because he knows we need to separate. My parent support says parents need time out too. She says parents throw tantrums, too.

Parent

3.2 Increased Efficiency of Community Based Services

The services PSS provide increase the efficiency of community based services to care for children with an SED in the least restrictive placement that will meet their needs.

The progress that has been made has not been necessarily with the child but a change in her home environment. The parent support worker played a key role. The parent had mental illness and so the parent support worker was very sensitive to that. Parent support was able to work with the parent to help her re-structure the environment and help the parent know how to parent this
kid. We have diverted this kid from a level 6 successfully and now things are going great.

**Direct Service Staff**

Parent Support Specialist services assist in translating the treatment process to parents, which helps them understand their crucial role in goal attainment. Through PSS, parents find constructive ways to be involved in their children's lives.

The parent has a person [PSS] that is there for them, helping them understand the process. This is very different than what parents are used to. With parent support, parents come to really understand the importance of investing a lot more time and energy into their children. That seems to be the number one importance of having a PSS with the family.

**Supervisor**

Providers value the perspective PSS bring to the treatment team.

She offers a perspective that I can't, and that's really great. I don't have children, so some of my parents look at me and they don’t find my information very credible, so when I refer PSS to them she can give them a perspective that I couldn't offer to the parents otherwise.

**Direct Service Staff**

4. **Characteristics, Life Experience, and Skills of PSS**

Parent Support Specialists bring a wide variety of experiences and skills to their work. Over half of the PSS survey participants have served as PSS for 1 to 2 years and almost one quarter from between 5 and 7 years, with an average longevity of over 3 years. The majority of PSS participants were parents of children living with a serious emotional disturbance (SED). Focus group findings indicate that their shared experiences as parents allowed PSS to develop close bonds with parents. Thus, effective PSS need advanced skills to manage therapeutic relationships with parents.

These skills evolve from personal experience (e.g., trial and error), training, and on-the-job learning. Supervision and mentoring relationships with more seasoned PSS peers help PSS to find a personal balance.

5. **Training for Parent Support Specialists**

At the time of this study, the state mandated training was provided by Keys for Networking, a parent advocacy organization. Parent Support Specialists require training to develop the necessary diplomacy skills to manage therapeutic relationships with parents. Training is most effective when provided by PSS who are employees of a CMHC. Lastly, training plays an important role in helping to integrate the PSS role into the treatment teams. Beginning in July 2006, the training was provided by The Kid’s Training Team.
which is a statewide collaborative effort of the Kansas Department of Social Rehabilitation Services (SRS), Wichita State University (WSU), the Training Advisory Group (TAG), and Title XIX Medicaid Programs. Parent Support Specialists are required to complete the training within one year of the date they are hired. The training includes completion of an online curriculum and two days of face to face training with other CBS providers.

6. Integrating the PSS Role Within Treatment Teams
A team approach helps to integrate the PSS role within treatment teams. Parent support specialist roles and tasks must be clearly defined by treatment teams. All members (families, therapists, case manager, etc.) must understand the unique perspective PSS bring to treatment teams. In addition, PSS must be careful to set limits and engage parents in activities that tie into treatment goals. Regular communication between the treatment team members is most helpful to establish complimentary tasks on the treatment teams. Feedback from PSS stressed the need for more cross training with case managers and PSS.

There needs to be more cross-training, and understanding of each other’s roles and about teamwork and how we can fit together. Good teams understand each other and do whatever it takes for families. That’s what it should be about, the families.

Parent Support Specialist

7. Supervision of Parent Support Specialists
The majority of supervision was provided by an administrator or a clinician. Most PSS have meetings with supervisors at least weekly and experience their supervisors as accessible and helpful. Supervision was most utilized for refining skills to manage the therapeutic relationships with parents as well as finding a balance between the advocacy and employee roles.

8. Access to Parent Support Specialists
The majority of families were already in CMHC services when they were referred to PSS services. The majority of PSS reported that families were isolated, under stress, experiencing crises, or having difficulty with parenting. In focus groups, administrators conveyed that PSS services were reserved for families with the highest needs due to the limited number of PSS staff available. Overall, parents said they would have liked to have been referred sooner. Parent support specialists also concluded that earlier referral would help to prevent crises thereby reducing the intense level of support PSS must provide when families have reached a crisis state.

This finding was strongly supported in feedback from PSS.
Families don’t come to us stable; they come to us in crisis and that’s where we can get in and help hold that parent up through that crisis and then help them navigate the system. The earlier the better!

Parent Support Specialist

From feedback, PSS also stressed the importance of educating families about how PSS can help and the kind of tasks they can help with. When parents begin services, having a PSS with the perspective and background PSS bring could also help parents feel less judged.

9. Limited Supply of Parent Support Specialists
There is a need for more PSS. Most agencies employed full-time PSS with benefits. Caseload sizes varied from agency to agency (range 2 to 80) with an average of 35 families per caseload. Agencies said they did not have a way to generate enough revenue to fund more positions.

POLICY IMPLICATIONS & NEXT STEPS

The present study illustrates the value and effectiveness of PSS services in the children’s mental health system of care in Kansas. In order to sustain the current infrastructure of PSS services, stakeholders should consider the following steps: 1) secure funding to increase availability of PSS services; 2) target specific needs and increase earlier access of available PSS services; 3) continue to integrate the PSS role into treatment teams; and 4) continue researching the nature of effective PSS services within the community mental health system.

1. Secure Funding
Exploring program ventures with other child serving systems such as family preservation, juvenile justice, child welfare, schools, and early intervention will likely provide opportunities to increase staffing of PSS positions in communities. In addition, these efforts should incorporate an evaluation component to continue to document the effectiveness of PSS services across child serving systems. Effectiveness findings should be utilized by state officials with Medicaid and the Kansas Children’s Cabinet to sustain the current funding mechanisms.

2. Target Specific Needs and Increase Earlier Access
The present study supports the idea that earlier access to PSS services would prevent the need for an intense level of support at the onset of the referral and has the potential to prevent crises, which may be a cost saving approach. Parent support services can be targeted to meet specific needs at an earlier point in treatment. Stakeholders can explore the development of a needs assessment, limit caseload sizes, and incorporate realistic billable expectations for PSS.
3. Continue to Integrate the Parent Support Specialist Role
As identified in the literature review, providing training and supervision that are sensitive to the unique helping relationships PSS form with parents are challenges inherent in integrating the PSS role into mental health treatment teams. Key findings in the supervision and training section support that Kansas faces the same challenges. The current PSS training can continue to address the development of diplomacy skills needed to help PSS utilize their personal experiences as parents. In addition, the supervisory training could address how supervisors have a crucial role in helping staff understand the unique approach and value of PSS services on treatment teams. The supervisory training could also address the importance of regular supervision with PSS that emphasizes understanding of agency dynamics and the PSS role within the treatment teams.

*It is a tricky balance because PSS are representing the mental health center, but PSS are also advocating for their client. PSS need to appease two different audiences at times. Our PSS has learned how to do both. But it takes awhile to be able to do that.*

_Supervisor_

4. Continue Study of Effective Parent Support Specialist Services
The present study shows how the unique perspective of the PSS supports the transformation to a family driven system of care and improves treatment outcomes. Future research will continue to examine the effectiveness of PSS services, particularly as it relates to child and family outcomes.

4.1 Study Impact of Parent Support Specialists’ Relationships
Future study could show when and how PSS relationships are most effective at enhancing parent, child, and family outcomes. For instance, future study could examine the development of the parent and PSS relationship over time and in relation to outcomes (child behavior and emotional functioning, caregiver strain, family empowerment, and goal attainment). This study is an important initial step in establishing evidence that PSS services lead to improved child and family functioning within a community mental health system of care.

4.2 Engage Key Stakeholders in Development of Continued Study
Key stakeholders (families, PSS, case managers, therapists, and CBS directors) should be engaged in the process of development of future research. Specifically, research partners can present key findings from the present study to families, PSS, case managers, therapists, and CBS directors and gain their insights regarding the process for continued study. Parent Support Specialists and their evaluation partners should continue to work together to document the evolving role parents have in primary decision making roles in the system of care.
4.3 Assess Cost in Relation to Children’s Outcomes

Assess cost and children’s outcomes with the addition of PSS services to CBS treatment. Client Status Report (CSR) outcomes may indicate that youth whose parents received support also received more effective services. Furthermore, qualitative findings suggest that PSS services increase the efficiency of CMHC services by preventing the potential to access more restrictive services (e.g. psychiatric hospitalization). If parents who are receiving PSS services utilize fewer services overall, there may be some cost savings. A study of PSS services could be designed utilizing existing Medicaid service utilization data and CSR outcomes to assess the impact of PSS services on the overall cost of CBS services.
TABLE OF CONTENTS

RATIONALE FOR STUDY

Introduction ....................................................................................................................1
  Background of Community Based Services Programs .............................................2
  Parent Support in the Literature ...............................................................................5

THE STUDY

Study Purpose ..............................................................................................................12
Methodology ................................................................................................................12
Study Questions ...........................................................................................................13
Findings ........................................................................................................................14

WHO ARE THE PARENT SUPPORT SPECIALISTS?

1. Demographic Characteristics ...................................................................................15
2. Personality Characteristics, Life Experience, and Skills ........................................17
   2.1 Varied Life Experiences, Personality Characteristics, and Skill Sets..............17
   2.2 Personality Characteristics, Life Experiences, and Skills of Effective PSS ...18
      Summary Study Question 2 ....................................................................................26

PARENT SUPPORT SPECIALIST PROGRAMS

3. Components of a Parent Support Program .............................................................27
   3.1 Parent Support Program Components ..............................................................27
   3.2 Frequencies of PSS Program Components Provided .......................................28
   3.3 Curricula Utilized .............................................................................................29
   3.4 Receptivity to Training .....................................................................................29
   3.5 Summary of Primary Functions From Focus Group Data ..................................30
      Summary Study Question 3 ....................................................................................40

4. Access to Parent Support Services .........................................................................41
   4.1 Referral Sources for Parent Support Services ..................................................41
   4.2 Referral Process ...............................................................................................41
   4.3 Benefits of Earlier Referrals ............................................................................42
   4.4 Family Situation When PSS Services Begin ...................................................42
   4.5 Access to Parent Support Services and the HCBS-SED Waiver .....................44
      Summary Study Question 4 ....................................................................................45

5. Populations Served by PSS ....................................................................................46
   5.1 Strengths of Families Served ...........................................................................46
   5.2 Specific Family Situations ...............................................................................46
      Summary Study Question 5 ....................................................................................47

ADMINISTRATION OF PARENT SUPPORT SERVICES IN
COMMUNITY BASED PROGRAMS

6. Parent Support Specialists and Case Managers ....................................................48
   6.1 Area of Focus ...................................................................................................48
   6.2 Parent Support Specialist Approach ................................................................48
   6.3 Teamwork ........................................................................................................49
TABLE OF CONTENTS, CONTINUED

Summary Study Question 6 ............................................................................................ 50
7. Training and Supervision ......................................................................................... 51
  7.1 Training ............................................................................................................. 51
  7.2 Supervision ...................................................................................................... 53
Summary Study Question 7 .......................................................................................... 56
8. Education and Professional Credentialing ............................................................... 57
  8.1 Benefits ............................................................................................................ 57
  8.2 Consequences .................................................................................................. 57
Summary Study Question 8 .......................................................................................... 58
9. Dynamics Surrounding Staffing .............................................................................. 59
  9.1 Number of Staff Designated to Provide Parent Support .................................. 59
  9.2 Caseload sizes for Parent Support Specialists ................................................. 59
  9.3 View of Parent Support Specialists by Other Agency Service Providers ...... 61
  9.4 Membership on Wraparound Teams ................................................................. 62
  9.5 Access to Support in Agencies ........................................................................ 62
Summary Study Question 9 .......................................................................................... 63
10. Billing Mechanisms ............................................................................................... 64
  10.1 Parents Served by Payment Source .................................................................. 64
  10.2 Billable Expectations ..................................................................................... 64
  10.3 Tracking Family-Centered System of Care (FCSC) Funding....................... 65
Summary Study Question 10 ....................................................................................... 66
11. Value of Parent Support Service .............................................................................. 67
  11.1 Services Related to the Goals on Youth’s Plans of Care ............................... 67
Summary Study Question 11.1 .................................................................................. 69
  11.2 PSS Services Provided to Parents Are Helpful to Their Children ............... 69
Summary Study Question 11.2 .................................................................................. 70
  11.3 Some PSS Functions More Helpful Than Others? ........................................ 70
Summary Study Question 11.3 .................................................................................. 71
  11.4 Improvement in Conditions for Which Children are Receiving
    Community Based Services? ............................................................................. 71
Summary Study Question 11.4 .................................................................................. 73
12. Children Whose Parents Receive PSS Services Differ From Those
    Whose Parents Do Not Receive These Services .................................................. 82
  12.1 Residential Status ......................................................................................... 82
  12.2 Law Enforcement Contact ............................................................................ 83
  12.3 Academic Performance .................................................................................. 83
  12.4 School Attendance ........................................................................................ 84
  12.5 Child Behavior Check List (CBCL) Scores ................................................... 85
Summary Study Question 12 ....................................................................................... 86

VALUE OF PARENT SUPPORT SERVICES

CLIENT STATUS REPORT OUTCOMES

Children Whose Parents Receive PSS Services Differ From Those
Whose Parents Do Not Receive These Services .................................................. 82

12.1 Residential Status ......................................................................................... 82
12.2 Law Enforcement Contact ............................................................................ 83
12.3 Academic Performance .................................................................................. 83
12.4 School Attendance ........................................................................................ 84
12.5 Child Behavior Check List (CBCL) Scores ................................................... 85
Summary Study Question 12 .................................................................................. 86
### TABLE OF CONTENTS, CONTINUED

#### SUMMARY AND DISCUSSION

1. Support of Family Driven System of Care ............................................................. 87  
2. Efficacy of Parent Support Specialist Services....................................................... 87  
3. Value & Helpfulness ............................................................................................... 88  
4. Access ..................................................................................................................... 90  
5. Challenges Integrating the Parent Support Specialist Role .................................... 91  
6. Training and Supervision ....................................................................................... 91  
7. Benefits and Consequences of a Credentialing Program ........................................ 92

#### POLICY IMPLICATIONS AND NEXT STEPS

1. Funding to Increase Availability of Parent Support Services................................. 93  
2. Specific Needs and Earlier Access ......................................................................... 94  
3. Continued Integration of the Parent Support Specialist Role .................................. 95  
4. Continued Study of Effective Parent Support Services .......................................... 96

#### REFERENCES

References.................................................................................................................... 98

#### APPENDIXES

Appendix A:  Parent Support Specialist Focus Group Questions.............................. 102  
Appendix B:  Parent Support Specialist Questionnaire ............................................. 104  
Appendix C:  Parent Focus Group Questions ............................................................. 108  
Appendix D:  Direct Service Staff Questions ............................................................ 110  
Appendix E:  Community Partner Questions ............................................................. 112  
Appendix F:  Supervisor Questions ........................................................................... 113  
Appendix G:  Administrative Staff Questions ........................................................... 115  
Appendix H:  Parent Questionnaire ........................................................................... 116
INTRODUCTION

The Kansas Social and Rehabilitation Services – Division of Health Care Policy (SRS/HCP) contracted with the University of Kansas School of Social Welfare (KU) to examine issues surrounding parent support services offered as a part of Community-Based Services (CBS) provided by Community Mental Health Centers (CMHCs) within the Kansas public mental health system. This request arose from findings of a three-year statewide study of wraparound fidelity and quality of care within the Kansas system, previously conducted by KU (Barfield, Corrigan, Chamberlain, Hong, & Barket, 2006). In that report, the large majority of parents offered especially positive comments about the value and helpfulness of parent support services. In some cases, the parent support specialist (PSS) was the first person from the center that parents met. Parents found this connection extremely valuable and they had an ally in the sometimes complex process of beginning services.

The current structure and goals of the Kansas public mental health system as well as its development undergird this study. The public system in Kansas is comprised of supports that vary from highly restrictive (hospitals) to non-restrictive (CMHCs). One guiding principle of the system of care is that services and supports are best provided in the community when possible.

The Kansas SRS/HCP has adopted a philosophy of community-based, strengths-oriented, family-centered service provision that defines the delivery of mental health services to children and families in CBS programs. In this model, the client and family are seen as integral members of a team, actively participating in the development of goals and objectives and the selection of appropriate services. Taken even further, family members are seen as experts who can offer the insight and experiential details that lead to the identification of strengths and needs, accurate diagnoses, and effective services. This approach to service provision planning is facilitated through a wraparound model whereby parents have the option to invite other family members or caregivers, mental health center staff, significant others, school personnel, and members of the community to participate in the planning process as equal team members directing the provision of services. This individualized process seeks to coordinate mental health services with other community services and resources to develop the most comprehensive and realistic plan possible.

Community-Based Services are for families and children who are living with Serious Emotional Disturbance (SED) and are in need of specialized services. CBS programs provide a wide range of supportive and therapeutic services to children and families. Among the array of services offered are attendant care, case management, crisis stabilization, family therapy, home-based family therapy, individual therapy, medication management, parent support, psychosocial groups, respite care, and wraparound meetings.
Background of Community-Based Service Programs and Parent Support in the State of Kansas

The offering of CBS to children living with SED in the State of Kansas is relatively new among services offered by CMHCs. During the 1980s, the Kansas Medicaid program began reimbursement of children’s case management, hospitalization, and home-based family therapy, providing the incentive for the beginning development of CBS statewide. In 1990, the Mental Health Reform Act was passed, which was the first statewide effort at reforming mental health services in the state. This act brought funding and attention to the mental health arena, primarily for adults. Additional initiatives and funding streams continued throughout the 1990s to support the reform efforts, including reduction in the use of state mental health hospital beds and closure of one of the state mental health hospitals. The funding that had been spent on maintaining the state mental health hospital beds was diverted to CMHCs in an effort to assist people with mental illnesses in the community where they had other supports as well. Although the primary beneficiaries continued to be adults, funding for children’s programs provided a substantial boost to the fledgling CBS programs developing in many CMHC catchment areas.

In the 1990s, the shift for children began. In 1994, five CMHCs in southeast Kansas and one CMHC in south central Kansas received funding over a period of 5 years under a large federal grant through the Substance Abuse and Mental Health Services Administration (SAMHSA), Center for Mental Health Services, U.S. Department of Health and Human Services. This funding had multiple foci including implementing a comprehensive approach to children’s mental health, financing a broad array of services and supports, individualizing care for children and families, broadening the range of services and supports, and strengthening family and youth partnership and family support (Department of Health Services and Human Services, 2004, p. 3). Parent support and involvement was a key piece of this SAMHSA grant (named KanFocus). An administrator at one of the funded centers when KanFocus began indicated that SAMHSA reviewed the initial grant proposal and returned it due to inadequate active parent involvement (J. West, personal communication, March 14, 2006). Therefore, parent support was added to the proposal. A parent advocacy group was contracted to provide parent support positions for the six centers. The SAMSHA 2000 Annual Report to Congress on the Evaluation of the Comprehensive Community Mental Health Service for Children and Their Families Program discussed family involvement strategies. The report indicated the following:

At the system level, family involvement in the Children’s Coalitions was weak, and agencies had not effectively incorporated family input into their operations and management. During the last year of funding, KanFocus ended the contract with the family organization for family advocates because they lacked adequate supervision and training. However, all of the family advocates who previously were hired as contractors became employees.... (p. 13)

Therefore, in 1999, according to two CMHC administrators from funded sites, eight individuals who had provided parent support under the federal grant became employees of the CMHCs (S. Duncan, personal communication, June 7, 2006; J. West, personal communication, March 14, 2006). Since that time, the number of service providers, who
became known as parent support specialists (PSS), has grown and spread to all CMHCs within Kansas.

Laura Howard, Assistant Secretary of Health Care Policy for SRS, said the service model used by the KanFocus federal grant for serving families with children living with serious emotional disturbance should be praised. She indicated the concept of ‘wrapping’ services around families through interagency coordination – along with an emphasis on parent involvement – made it possible for many children to remain in their communities and with their families. Howard also stated that the KanFocus model, along with the positive outcome data provided, was instrumental in the Kansas Legislature’s decision to allocate $5 million in grants to the community mental health system statewide (Kansas SRS, 2000, p. 2). This statewide grant program is called the Family-Centered System of Care (FCSC).

Thus, in 1999, the Kansas Legislature continued the aforementioned momentum by appropriating funds via the Kansas Children’s Cabinet, specifically to further expand and/or enhance the array of mental health services for children and families through the FCSC. The Kansas Social and Rehabilitations Services Division of Health Care Policy is the administrator of the FCSC grant funds via contractual agreement with the CMHCs. Appropriation of funds was determined via a request for proposal process in which each CMHC across the state was required to develop a strategic plan. The plan addressed service delivery in three broad areas: increase community collaboration on behalf of service delivery, provide parent support services to families, and increase/expand the array of CBS for children with SED (Activities in Kansas Related to Goal 2-Mental Health Care is Consumer and Family Driven retrieved October 5, 2006, from http://www.srs.kansas.org/hcp/MH/draftNF-Activities.pdf). Thus, each CMHC has an individualized plan that addresses how FCSC grant funds will be utilized to provide parent support services. In addition, each strategic plan was required to address how much revenue CMHCs expected to generate as well as show how the fees would be folded back into the programs to continue to increase service delivery capacity.

Earlier, in 1997, SRS/HCP received a state HCBS (Home and Community-Based Services)-SED (Series Emotional Disturbance) Waiver for children and youth living with SED through the federal Centers for Medicare and Medicaid Services (CMS). This Waiver became a resource within the children’s CBS system that allowed the state to provide mental health services through Medicaid to children living with SED at risk of state hospitalization. The Waiver also established expanded services, one of which is “Parent Support Education and Training.” This development made parent support a billable Medicaid service that can be provided to families on the Waiver. This contributed to the continued evolution of PSS services.

With the help and support of the state Mental Health Authority, a parent liaison position was established that focuses on addressing the issues affecting families with children experiencing SED and coordinates parent support efforts statewide. The parent liaison supported and helped establish the foundation for PSS statewide meetings. The first PSS statewide meeting was held on September 21, 2001. These meetings are held six times throughout the year in three different regions of the state. According to the current parent liaison, state statistics indicate that 28 parent support specialists were working within the system of care in 2001. This number was retrieved from the notes taken at the first
statewide meeting of parent support specialists. The parent liaison assisted the group in becoming an affiliate of the Association of Community Mental Health Centers of Kansas, Inc., in 2002.

At the current time, 62 parent support specialists (PSS) are employed in 26 CMHCs in Kansas. PSS within the CMHCs work to facilitate family empowerment and encourage full parent participation in the child’s treatment plan at school and in the family environment. Parent support specialists also provide parent education and information about community services, resources, trainings, and state/legislative meetings. The HCBS SED Waiver describes the PSS services.

Parent Support is a service that provides the training and support necessary to ensure engagement and active participation of the family in the treatment planning process and with the ongoing implementation and reinforcement of skills learned throughout the treatment process. Training is provided to family members to increase their ability to provide a safe and supportive environment in the home and community for the consumer. This involves assisting the family in the acquisition of knowledge and skills necessary to understand and address the specific needs of the consumer in relation to their mental illness and treatment; development and enhancement of the families specific problem-solving skills, coping mechanisms, and strategies for the consumer's symptom/behavior management; assisting the family in understanding various requirements of the waiver process, such as the crisis plan and plan of care process; training on the child’s medications or diagnoses; interpreting choice offered by service providers; and assisting with understanding policies, procedures and regulations that impact the consumer with mental illness while living in the community (Application for a 1915 (c) HCBS Waiver, HCBS Waiver Application Version 3.3 retrieved on June 7, 2007, from http://www.medicaidtraining.org/MedicaidTraining2.0/PDF/StatePlanTools/1915cSEDWaiverAmendment030107.pdf).

In response to needs expressed by parents and families across the nation, the President’s New Freedom Commission on Mental Health 2003 Report (Department of Health and Human Services) established six goals that were determined necessary to transform mental health in America. The Kansas Mental Health Coalition, in conjunction with SRS/HCP, the Association of Community Mental Health Centers, the National Alliance for the Mentally Ill—Kansas, Keys for Networking, the Mental Health Associations, and others, sponsored six conferences to help define priority needs that exist in the state and how they should be addressed. Goal Two of the Commission’s Report was “Mental Health Care is Consumer and Family Driven.” On June 16-17, 2005, a conference was convened in Wichita to understand the needs of parents, families, and consumers regarding implementation of Goal Two, particularly as it pertains to children and their families.

Larke N. Huang, Ph.D., a member of the President’s New Freedom Commission on Mental Health, opened the conference as featured speaker. The following principles are among those the Commission considered essential for transformation of mental health services for children:
1. Real and meaningful choices by consumers and family members, including parents of children, of treatments, services, supports, and providers.
2. Promotion of resilience, recovery, prevention education, and reduction of stigma.
3. Elimination of disparities in access to quality care, by minority populations and others who are underserved, including those who live in rural areas.
4. Protection and enhancement of the rights of persons who have serious mental illnesses.
5. Utilization of service delivery approaches that include the entire family, in home, school, and community-based settings.
6. Assurance of resources necessary to carry out transformation in a consumer and family driven system of care.

Raymond Crowel, Psy.D., of the National Mental Health Association, defined family-driven care as families of children having a voice in

1. Choosing supports, services, and providers.
2. Setting goals.
3. Designing and implementing programs.
5. Determining the effectiveness of all efforts to promote the mental health and well-being of children and youth.

Feature presentations were followed by small-group discussions on opportunities and barriers experienced by parents in parent/child access, involvement, and special needs. Participants, including over 60 parents, identified as their highest priority parent education and involvement in all aspects of programming and service delivery for a child. Parents said they want to have their children living at home and participating with other children in community activities and services. They expect coordination of services and want to be respected by professionals as having an equal voice in decision making. In addition, family support and education, along with in-home therapy, respite and/or attendant care, case management, and wraparound services were reported by families to be important in maintaining their children in the home. Respect for and support of each family in its cultural values, traditions, language, and special character were also reported as necessary for effective communication and service delivery. The needs expressed in the Commission’s Report and discussed at the Kansas conference are consistent with those addressed in parent support programs. Parent support specialist services assist families in their communities in accessing mental health services and other resources necessary for their children to live and grow safely in their homes and communities and to succeed in school (R. Mohr, personal communication, May 2006).

**Parent Support in the Literature**

**Review of the Literature in Children’s Mental Health**

A considerable amount has been written about the role of families and their unique responsibilities as caregivers both in popular press and professional literature on child-serving systems (Osher & Osher, 2002). The continuum of roles for families in their children’s care has expanded from involvement to leadership. Family members as leaders
in the child serving systems are collaborating with professionals to function as advisers, service planners, providers, and evaluators. The goal of such collaboration is to merge the unique talents, perspectives, and abilities of all the stakeholders on behalf of the child (DeChillo, Koren, & Mezera, 1996). Family support programs are among such initiatives that encourage family involvement in defining and determining the services, with family support as its key objective. Family support programs are also called by other names such as peer-to-peer or parent-to-parent support programs.

**Parent-Professional Partnership**

Recent family support initiatives emphasize families taking on a more active role. Though programs are highly diverse, their ultimate goal is to strengthen informal support systems and networks so that families and communities can be independent of more formal programs (Zigler & Black, 1989). Karp (1996) reviewed the values that guide family support programs; these include 1) focusing on the family and community, 2) placing decision-making control in the hands of families, 3) involving families throughout the process, and 4) ensuring program flexibility (p. 292). Karp further emphasized that family support services can include general support, attending an agency meeting, in-home assistance, transportation, cash assistance, training, and recreation.

Osher and Osher (2002) pointed out that the stigma associated with emotional disturbance contributes to isolation of families and reluctance on the part of the service providers to adopt policies and practices that provide families an opportunity to have voice in the decision making process. The authors provided a framework for providers and families to facilitate the paradigm shift from provider-driven to family-driven services. Provider-driven approaches constitute the traditional approaches to service delivery and are grounded in the idea that only professionals are qualified to apply a specialized body of knowledge. Family-driven approaches, on the other hand, encourage processes where goals are assessed in true partnership with families and are grounded in the experience, expertise, hopes, desires, and needs of the children and their families. A model based on professional-parent partnership emphasizes power sharing and dialectical process among professionals and participants. The services provided by such a program include a constellation of formal and informal services developed in response to the needs of the entire family, including the child with a mental health problem (Freisen & Huff, 1996).

Family support programs employ family-centered approaches in the delivery of services. These approaches are rooted in an ecological conception of the family as the primary resource for a child’s well being. The ecological perspective emphasizes creating a support system by making the family unit and the immediate environment surrounding families conducive to the development of the child (Comer & Fraser, 1998). An important contribution of the family-centered programs has been to involve family members as professionals. Often parents of children who receive or have received services within a system of care become the providers of services to other parents, as parent support service providers.
Relationships Based on Shared Experiences

The impact of parent support interventions lie in the mutual connections that are recognized in the initial interactions between parent providers and other parents. Early emphasis upon similar shared experiences tends to create a foundation on which a relationship can be built (Ireys, Devet, & Sakwa in Burns and Hoagwood, 2002). With careful attention to the timing and therapeutic value of self-disclosure, parents as professionals bring credibility to their work which reinforces the value of the relationship.

Components of Parent Support Programs (Roles/Functions of Family Support Professionals)

According to Osher, deFur, Nava, Spencer, and Toth-Dennis (1999), specific job titles given to new roles assumed by family members in the systems of care vary from community to community; however, they can be broadly categorized as systems of care facilitators. The term ‘systems of care’ is used by the report to reflect the key feature of the role, namely, family members using a variety of strategies to facilitate a positive working relationship between enrolled families and the systems of care. Family support professionals are identified by a variety of job titles such as family associate, family advocate, parent mentors, family resource developer, and family service coordinators.

Koroloff, Elliott, Koren, and Friesen (1994, 1996) indicated that a Family Associate in Oregon was a paid position with three main responsibilities that included 1) providing support, 2) providing information, and 3) linking families to resources. These associates, who were involved in rearing children with emotional or behavioral disorders, helped other families negotiate the system of care.

Evan et al. (1994) report that the City of New York has Family Advocates who serve as liaisons between families and professionals. Each of these advocates is involved in rearing at least one child with emotional or behavioral disorders. Their roles include representing families in policy meetings, facilitating communication between families and professionals, providing informal support to families through home visits and telephone calls, modeling self-advocacy, and helping families prepare for individualized education plan meetings.

Parent Connection in Baltimore, Maryland, offers another example of involving parents as providers. Parent Mentors in the program receive an hourly stipend for working up to ten hours a week. These Mentors are parents or guardians of adult children who received treatment between nine and fourteen years of age for a mental, emotional, or behavioral disorder (Osher et al., 1999).

The Regional Intervention Program in Nashville, Tennessee, and the Parent Educating Parent Program in Cleveland, Ohio, are community based programs providing family-centered services for young children with behavioral problems. These programs have involved family members both as volunteers and employees. The programs hire and train some parents to serve as case managers for new family members (Timm, 1993).

The role of Family Resource Developer evolved through several titles and job descriptions in the Community Wrap-Around Initiatives in LaGrange, Illinois. These professionals are
housed in a variety of community agencies and are able to work closely with school personnel, other providers, and clinical staff in the process of helping families (McCammon, Spencer, & Friesen, 2001).

Family support professionals have been designated as Family Service Coordinators in Rhode Island (Osher et al., 1999). They are hired by Project REACH, one of the grant communities funded under the Center for Mental Health Services’ Comprehensive Mental Health Services Program (Osher & Osher, 2002). While the specific job titles and job descriptions vary among regions, their duties include 1) scheduling case review meetings; 2) coordinating and scheduling appropriate participants to attend the case review meetings; 3) supporting and advocating for family needs; 4) documenting the confidentiality of client related information; 5) completing and maintaining REACH Rhode Island Evaluation forms; 6) following up with case review team members on their assigned tasks; and 7) working with families, parent organizations, and related services providers to disseminate information about the mental health system of care and other pertinent children’s mental health issues.

**Personal Characteristics and Background of Parent Support Specialists**

According to Osher et al. (1999), the characteristics that these facilitators possess in common include patience, compassion, and excellent listening skills. Perhaps these commonalities are attributable to the fact that almost all of the service providers have experienced the highs and lows of rearing a child with mental health needs (p. 30). These facilitators accept families, youth, and children unconditionally, without any judgments. They have been referred to as change agents who enable the systems of care to function successfully.

**Challenges**

Koroloff et al. (1994) drew attention to the fact that none of the locations employing Family Associates had prior experience working with family members in similar roles. As a result, both the administrators and family members faced the challenge of integrating the new role assigned to the latter. The challenge was to ensure that while the family associate's training focused on development of professional skills, it also capitalized on the expertise and experience for which they were hired. The challenge is to include information that will better prepare these professionals to work collaboratively with families and family organizations.

**Outcomes of Parent Support Programs**

The results of a quasi-experimental study by Koroloff and Friesen (1991) indicated that parent-to-parent support provided positive outcomes for families. Such support, whether in support groups or other forms, was important to families. Many parents in the study reported that interactions with other parents greatly contributed to their ability to cope with rearing a child with emotional difficulties.

Davis and Rushton (1991) found that delivery of services by health visitors trained in the basic skills of parent counseling had a positive impact on children and their families.
Parent counseling resulted in improved psychological functioning in mothers, improved family relations, and improved behavior of the children and their developmental progress. Further, there was evidence that certain difficulties could be prevented as a result of the intervention.

Results of a quasi-experimental study by Davis and Spurr (1998) indicated that health visitors, trained and supervised by child mental health specialists, were able to work successfully with parents of preschool children with psychosocial problems. These professionals were able to establish a mutually respectful partnership and support parents in managing their diverse problems. Relatively brief intervention had benefits, at least in the short term. This study found a statistically significant increase in the mothers' self-esteem, significant reduction in parental stress and anxiety/depression, and a significant improvement in the immediate environment for the children. Improvement in the children’s behavior was also reported.

In their quasi-experimental study, Koroloff et al. (1996) reported that family associates in Oregon were able to successfully provide low-income families of referred children with transportation, information about emotional and behavioral disabilities, and, most importantly, emotional support. Participating family members believed that these family associates not only helped other families but also sensitized administrators and providers to include more effective family involvement.

A multi-year evaluation of a parent support center using a qualitative design (Coady, Rothery, & Dennis, 1999) found that participants stressed the importance of the social and emotional support they received from each other and from the project staff. Meyer and Marcenko (1989) concluded that mothers caring for children with developmental disabilities experienced considerably less stress after being enrolled in the Michigan state program for a year as compared to the year prior to their enrollment.

A study by Osher et al. (1999 in McCammon et al., 2001) reported that in Illinois, following six months of working with Family Resource Developers, families increased their knowledge regarding their children’s problems and how to care for them and obtain services. These families also benefited from the help they received in obtaining financial assistance from public agencies and home-based services. The authors further indicated that the Family Service Coordinators (FSC) in Rhode Island are seen as the most essential feature of the REACH project and the source of its success. They reported that parents could relate to the FSC professionals better, which resulted in a more collaborative relationship between enrolled families and the service providers.

Ireys, Devet, and Sakwa (2002) employed a true experimental design to examine the Parent Connection Program in Baltimore. A control group received services as usual and an experimental group received a program called Parent Connections in addition to the services as usual. The 15-month family support and education program is designed to promote psychological and social functioning of children aged 9-14 years who have serious emotional or behavioral disorders. The goals of the program are to enhance parental recognition of 1) the types of social supports available, 2) knowledge of relevant parenting strategies, 3) ability to collaborate with professionals, and 4) sense of parenting efficacy (p. 162). The program provided social support through Support Partners who had reared
children living with SED and received 40 hours of skill building training. These partners called families twice a month. Education was imparted through 18 workshops facilitated by the Support Partners, the program director, and local mental health professionals. This education focused on supporting children’s positive behaviors, working with the mental health system, and self-care. At 12 months, children whose parents were in the experimental group had greater improvement in both Child Behavior Checklist (CBCL) and Child and Adolescent Functional Assessment (CAFAS) scores than the control group, but the differences between the groups were not statistically significant. The mean amount of parental support increased significantly more for parents in the experimental group than those in the control group. Parental depression and anxiety decreased more for the experimental group than the control group but differences were not significant.

**Value of Parent Support Programs**

It is apparent that family members as parent support specialists contribute two unique and important perspectives: one of caregivers rearing a child with special needs and one of consumers who navigate multiple systems, agencies, and community supports to obtain needed services. Service providers working with these family members can gain from their perspectives (McCammon, et al., 2001).

**Review of the Literature in Family Preservation**

**Program Overviews**

Due to the dearth of studies examining parent support in mental health, parent support in family preservation is considered. In their meta-analysis, Layzer, Goodson, Bernstein, and Price (2001) synthesized and quantified the findings of studies of 260 programs. The authors note that the definition of family support contained in federal legislation (the Omnibus Reconciliation Act of 1993) would include traditional family support programs whose primary mission is enhancing parents' capacity to support children's development, and which provide a variety of life skills workshops, parenting classes and parent support groups, parent-child groups and family activities, information and referral to other services outside the program, and advocacy for parents. In addition, the definition would include a set of more recent programs that have a primary mission other than enhancing parent capacity but which have incorporated family support into their program as an integral part of their services…. (p. A2-2)

Other definitions were also offered in the literature. In the face of a lack of consensus as to what constitutes a family support program, Layzer et al. (2001) developed a working definition of family support programs and interventions. This definition encompassed all services intended to improve child outcomes by strengthening the capacity of parents to support their child’s development. Operationally, the meta-analysis incorporated studies of any program or intervention aimed to improve child outcomes by enhancing parent capacity.
Program goals, in the order most frequently identified, included the following: improved parenting; child development; social support for parents; child/family health care; child abuse prevention, parent self-help, and empowerment; parent literacy and employment; parent community/school involvement; and child behavioral change (p. A3-2). Services were delivered in a variety of ways. A majority of programs used home visits for service delivery. More than half had school meetings and more than half had group activities at a program location. About 20% provided education services in a group setting.

More than 70% of programs were classified as research or demonstration programs, set up to test an intervention. Most ended when the evaluation was completed. The majority of programs operated at a single site. A quarter of the programs were in multiple states and a small number were statewide programs.

If programs targeted a specific population, they were considered on the basis of either environmental risk or biological risk related to the child. Environmental risk included factors such as family poverty, risk or instance of child abuse or neglect, and maternal depression or isolation. Biological risk included factors such as child developmental delays and behavior problems.

Almost every program offered some form of parent education, whether through home visits, information about parenting strategies, developmental and age-appropriate activities through classes for parents, parent groups, and printed materials. About half of the programs organized parent groups and other activities to provide social support and reduce isolation.

Outcomes of the meta-analysis fell in child and parent/family domains. The child outcome domains included cognitive development/school performance, social-emotional development, physical health, and child safety (including abuse and neglect). Parent/family outcome domains included parenting knowledge/attitude, parenting behavior, family functioning, physical and mental health, and economic self-sufficiency.

**Short-Term Effects of Family Support Programs in Family Preservation**

Improved outcomes for children is the ultimate goal of family support programs. Family support is seen as a means for helping children overcome risk factors and make accomplishments. However, most of the programs work primarily with the parents as agents of change. Weissbourd noted, “The capacity of parents to raise their children effectively is influenced by their own development” (Kagen & Weissbourd, 1994, p. 32). The authors identified the following guidelines for determining the quality of family support programs:

- programs recognize the importance of parental nurturing and seek to enhance parents’ capacity for growth and development; and
- programs understand that support can strengthen family coping capacities and strive to foster independence and empowerment (p. A3-14).
The family support programs included in the meta-analysis of Layzer et al. (2001) found programs that provide family support services had statistically significant effects on all domains considered including the following:

- children’s cognitive development and school performance;
- children’s social and emotional development;
- parenting attitudes and knowledge, parenting behavior, and family functioning;
- children’s physical health and development;
- children’s safety;
- parents’ mental health or risk behaviors; and
- improvement in families’ economic self-sufficiency (p. A5-2).
THE STUDY

Study Purpose

Parent support is a relatively new service provided by community mental health centers in Kansas. The service has been established as a promising practice by federal agencies such as the Substance Abuse Mental Health Services Administration, the Federation of Families, and the Research and Training Centers for Children's Mental Health (Ireys, et al., 2002). Kansas is one of the first states to offer parent support, a service offered as part of the HCBS-SED Waiver. As with any promising approach, there is a dearth of information in the literature regarding evidence-based practices for parent support in mental health systems of care. In a limited number of studies in mental health, parent support been shown to improve both parent and child outcomes. In addition, the service has demonstrated significant effects on both parent and child outcomes in family preservation. The state is in need of information that will build a knowledge base for sustaining the infrastructure of parent support services within the mental health system of care. The first goal of this study is to increase national knowledge about evidence-based practices. The second goal is to increase the understanding of effective parent support practices in Kansas and provide recommendations to the State of Kansas regarding how to support the development of family-driven services.

Methodology

Data collection commenced September 2005 and concluded in July 2006. This study utilized a mixed-method, multi-pronged approach that included the following:

- focus groups with community mental health center (CMHC) parent support specialists (PSS);
- focus groups with parents who receive PSS services at CMHCs;
- focus groups with CMHC direct service staff;
- interviews with CMHC administrative staff;
- interviews with persons providing supervision for PSS;
- parent questionnaires (quantitative and qualitative content);
- PSS questionnaires (quantitative and qualitative content); and
- use of an existing database from a previous study.

On three occasions, researchers from KU met with parent support specialists at their regional and state meetings to collaboratively develop study methodology. Parent support specialists provided insight surrounding issues such as the best sources of data to answer specific study questions, instrument development, and how to engage parents in focus groups. KU staff conferred with group members throughout the course of this study.

Site visits were made to eight CMHCs to conduct focus groups and interviews and to administer parent questionnaires. Community Mental Health Centers were selected based on state recommendations of exemplary PSS programs and to be representative of population density classifications of frontier, rural, densely-settled rural, semi-urban, and urban. During the site visits, parents completed questionnaires prior to focus groups, which
THE STUDY

lasted about one and one-half hours. All PSS at CMHCs were sent questionnaires for parents to complete. Parent questionnaires were then mailed to KU. Fifty-one PSS questionnaires were completed electronically and four were sent by mail to PSS for completion. Some questionnaires were finished at two state PSS meetings.

A draft report was sent out to a representative group of PSS stakeholders for initial feedback, based on state recommendations. Then the draft reports were sent out to all eight CMHCs as well as all PSS for feedback. Follow-up phone calls were made and emails sent to all PSS and all 8 CMHC program administrators. In addition, two researchers conducted a focus group at a statewide PSS meeting. Feedback is included throughout the report.

Study Questions

Data from a variety of sources, previously described, were utilized to answer the questions given below:

1. What are the demographic characteristics of parent support specialists?

2. What personality characteristics, life experience, and skills do parent support specialists bring to the helping process?

3. What are the components of a parent support program (primary roles and functions that parent support specialists perform)?

4. How do parents gain access to parent support services?

5. What populations are served by parent support specialists?

6. How do the primary roles and functions parent support specialists perform differ from those performed by case managers?

7. What training and supervision do parent support specialists receive?

8. What might be the benefits and consequences of parent support specialists pursuing additional education and professional credentialing?

9. What are the dynamics surrounding staffing of parent support specialist positions?

10. What billing mechanisms are utilized for parent support services?

11. What is the value of parent support services?
   11.1 Are parent support services related to the goals on youth’s plans of care?
   11.2 Are the parent support services provided to parents helpful to their children?
   11.3 Are some parent support functions more helpful than others?
   11.4 Are parent support services associated with improvement in the conditions for which children are receiving community-based services?
12. Do the Client Status Report outcomes of children whose parents receive parent support services differ from those whose parents do not receive these services?

**Findings**

Individual study questions will be given in the body of this report. Then, the data sources used to answer the questions and study findings will be provided subsequent to each question. On parent questionnaires and PSS questionnaires, many items contained a Not Applicable option and some parents and PSS did not respond to some items or questions. In sections where the full samples of participating parents or PSS are not represented, findings will be discussed in terms of the number of persons who completed specific portions of questionnaires without further explanation.

The qualitative findings will be presented in order of research questions. The qualitative data from focus groups was analyzed by two project staff. Based on a review of 39 transcripts, one project staff developed categories under each research question. The transcripts included a group of community partners who voluntarily came together to express their perspectives regarding PSS services. A total of 49 categories were developed with definitions. These categories were reviewed by an additional project staff to assess if the quotes assigned to each category were congruent with the category’s definition (internal consistency). In addition, each category was reviewed to make sure the category answered the proposed research questions (reliability). Differences in perceptions were discussed and noted and category definitions revised to capture all perspectives.
WHO ARE THE PARENT SUPPORT SPECIALISTS?

Study Question 1: What Are the Demographic Characteristics of Parent Support Specialists?

Study Question 1 was answered with data from the PSS questionnaires.

The demographic characteristics of Kansas parent support specialists (PSS) who participated in this study are delineated in Table 1. Of the 42 PSS who responded, 40 (95.2%) are female and two (4.8%) are male. The 38 PSS who reported ages ranged in age from 27 to 63, 32 (81.6%) of whom were over 40, with a mean age of 48.1. The racial composition of the group included a large majority of Caucasians (90%), three (7.5%) Latina/Latinos, and one (2.5%) First Nations. More than half of the respondents were married and almost 40% were divorced. Of the 42 PSS, 30 (75%) are or have been parents of children living with a serious emotional disturbance (SED). Over half of participants have served as PSS for one to two years and almost one quarter from between five and seven years, with an average longevity of over three years.
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<td>Mean Number of Years/Months Worked (Longevity)</td>
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Study Question 2: What Personality Characteristics, Life Experience, and Skills Do Parent Support Specialists Bring to the Helping Process?

In addition to the PSS questionnaires, this question was answered with qualitative data from focus groups with PSS, parents, and direct service providers as well as interviews with administrative staff and persons providing supervision for PSS.

2.1 Varied Life Experiences, Personality Characteristics, and Skill Sets

On the questionnaires, parent support specialists described a wide variety of life experiences and skills they bring to the helping profession. Primary among these attributes were the experiences and skills derived from parenting a child living with serious emotional disturbance. These factors afford PSS a unique ability to develop rapport and therapeutic relationships with parents. Parents see PSS as someone who has been there and understands them as well as the joys and challenges of living daily as parents of children with SED. Other life experiences and skills were listed by PSS on questionnaires. The most commonly identified experience was having a child, partner, or other family member living with a mental illness. Other background information included the following:

2.1.1 Work Experience & Educational Background

- Worked with Family Preservation.
- Worked at Job Corps, in foster care, and as a case manager.
- Worked in residential placements for behavioral disordered juveniles and adolescents; worked in community recreation for special population.
- Worked in special education classrooms and group homes.
- Worked as a case manager.
- Worked in criminal justice.
- Worked as an interpreter.
- Elementary education training; B.S. in Psychology/Family systems.
- M.A. in Human Development; MSW.
- Dual majors in Psychology and Rehabilitation Services.
- Associate’s degree in Travel and Management.
- Degree in Sign Language.

2.1.2 Community Resource Cultivating Experiences

PSS are especially adept at cultivating community resources. On the questionnaires, they described how they were able to do so, including

- utilizing years of personal experience;
- networking/maintaining good relationship with other community supports; and
- attending community meetings and gathering information.
2.2 Personality Characteristics, Life Experiences, and Skills of Effective PSS

In focus groups, participants were asked about personality characteristics, life experiences, and skills PSS need to have in order to be effective. Some common themes emerged from the qualitative data. However, personality characteristics, skills, and life experiences are difficult to parcel and are best conceptualized by this analysis as overlapping and interacting.

Because the relationship is the therapeutic tool you need to have someone that can therapeutically manage that relationship, so judgment is key. Sometimes people intuitively walk in and can do that. Other people need some training or some background, and that’s true for parent support workers, that’s true for therapists, that’s true for case managers, but judgment I would say is a critical piece of that. It’s going to have to be somebody that’s pretty outgoing. They don’t have to be so outgoing that they never meet a stranger, but they have to be able to put people at ease and relate to them. So managing that relationship, reading people for what their need is and for where they’re at and having some flexibility to say here’s my style. Here’s what I believe works. But that’s what works for me and I recognize you’re coming from a different place and therefore because you have a different package that you’re walking around with, we have to approach things from a different way. So having that capacity for an eclectic approach in managing I think is critical.

Community Based Services Supervisor
2.2.1 Personality Characteristics

- **Engaging & Non-threatening Approach**

Outgoing, compassionate, common sense…I would agree with all of those. I guess all those characteristics have to get down to that parent’s level, to be very nonjudgmental with that parent. Take that parent where they are. It doesn’t matter who the parent is, what the home looks like. It has to be a person who can go in and have all of those characteristics to make that parent feel comfortable.

*Community Partner*

- **Flexible, Accessible, Effective Listeners**

She listens and she gives suggestions. If I call her, she will call me back. Some people at other agencies, like she said, different agencies, other therapists, the case manager, sometimes it takes days for those people to call back. I know everyone’s busy, but my parent support worker will call me back within that same day. Without my parent support worker, I would have given up, too, like she said. Because everything is so confusing, and they’re supposed to do this and they’re supposed to do that, and some of them don’t do it, and this and that, and it’s just all craziness. And when you have a child that’s out of control and you need help, that’s what my parent support has given me.

*Parent*

No matter what she’s doing, a lot of the time when you go in there and you tell her this is going on, she always drops what she’s doing. She’ll tell you I have 5 minutes, but she’ll sit there and tell you what you need to know. She might be on her way out the door and on her way out the door she’s telling you oh, do this, do that. It’s on my desk. She’s always really available.

*Direct Service Staff*

- **Committed and Persistent**

Staff and families say they follow through on finding information and fulfilling requests.

If you have a question and she does not know it, she’ll go I don’t know, but we’ll find out. And if she can’t find it by the next appointment, she goes I haven’t found it yet, but I haven’t quit looking. She remembers from one meeting to the next what has been on. She can tell you right now what happened 4 years ago with my kids. And how she does it I don’t know, because I don’t even remember half of it. She’s just a special person. I think a lot of her job that is done so well here isn’t so much contributed to the job as it is to the person.

*Parent*
She’s not a quitter. No, she’s not. She’ll stay in there and fight. She’s more like a pit bull. She sinks her teeth and she keeps going.

Parents

One thing I’ve picked up on is that they’re advocates, and I think that’s probably fairly consistent. It’s a fairly consistent attribute that I see in most of our parent support workers. That if there’s a need and they don’t know the answer, then there’s a drive there to find out. So advocacy and also drive or inquisitiveness, kind of combined together, I see as being their attributes. Perseverance, they never let it go until it’s done or changed.

Administrative Staff

- Authentic, Honest, Open, and Direct

Families, CMHC service providers, and administrators report that communication is honest, open, and direct. Parent support specialists are authentic and focused on priorities. Honest feedback is given and encouraged.

I would just say honest and direct. She is focused on the priority. I think also the emotional detachment that she’s able to have balances my emotional attachment. It works well, because it’s hard to take a step back as a parent and say okay, let go of the guilt. Let it go. Focus on following through. She calls me on it. She says “uh-huh and the consequences? Well, the reason he keeps doing this is because you don’t follow through. Well, you know what, she’s right.”

Parent

The rest of them just beat around the bush. They’re not straightforward. She just puts it out on the table. She’ll flat tell you, you may not like what I’m going to tell you, but this is the way I see it, this is what I’m going to tell you, and you can either accept what she knows or not accept it, and she’s fine with that, but at least she’s told you. She’s very straightforward.

Direct Service Staff

I think we really do encourage very direct feedback and sometimes it takes a while for parents to understand that we can accept criticism and feedback and if they don’t like the job we’re doing they can have a different parent support. So we start with our role and say if you don’t like this come to us first. If you can’t come to us, go to a different team member. If you’re not comfortable with that you can go to the director, but don’t put up with something that you’re not satisfied with.

Parent Support Specialist

- Passionate

I believe that everybody stands a chance, everybody’s learning lessons. I can’t wait to see what I learned today. I never know what I’m going to learn on any given day.
What other job can you, number 1, set your schedule, have all the community contacts, support people in a positive way, absolutely love the people I work with and I work for. It’s a win-win situation. The best thing of all, my child got me this job.

Parent Support Specialist

- Evolving and Adaptable

Parent support specialists are evolving and adaptable to change and ready to learn new information.

She’s very knowledgeable about what she’s doing. She brings in new techniques. She’s constantly updating. She’s like oh, there’s a new video out. I’m going to get it and review it and see what I think of it. So she’s constantly trying to upgrade and continue her education to educate us better. She wants the parents involved in more than just whatever you have to do for your child. She’s like there’s other parents out there that are going through the same thing. She lets you know you’re not the only one. She’s got the experience from her own children that she’s dealing with that she’s able to give us some insight and some hindsight on her part. This didn’t work, and you’re doing it too and it’s probably not going to work for you.

Parent

In a focus group with the statewide PSS group, there was evidence of a process happening in the group, where they share, network and learn from one another. In this process they confront one another’s misconceptions/perceptions for the purpose of establishing a better understanding of the work they are doing.

One PSS said the following:

Case managers tend to look at our work with parents as triangulation. They will look at it like that. They feel very threatened by parent support workers sometimes. I’d say about 70% of them are really happy at having parent support because it does free up a lot of time. But there’s that small portion that think we are stepping on toes. They’re too close to the parent.

Feedback from PSS indicates that not all PSS feel this way but some may. The comment from another PSS directly following this statement:

This is going to go back to even maintaining your composure. One thing that, I’m saying this for your benefit and everyone else’s, if you can always remember there’s a chance that you’re wrong. It puts everything in perspective. Your opinion is just that: your opinion. And you could be wrong. And if you always remember that your opinion could be wrong, you could be doing a fine job and the best interests of the child will be served.
As discussed later in this report, there are some challenges to integrating the PSS role within treatment teams. Determining the value of all team members despite the similar roles and functions is one such challenge that will be discussed later in this report.

2.2.2 Skills

Though skill sets varied somewhat depending on the participant groups, there were a common set of skills reported by many participants as necessary to perform the job effectively.

- Diplomacy Skills

Effective parent support specialists possess a high level of diplomacy skills. The focus group participants identified numerous situations where PSS handle potentially hostile situations in a skillful way to reduce tension and bring about a team approach.

This diplomacy requires PSS to be able to understand diverse perspectives of a situation while presenting themselves in such a way that they are able to achieve the best possible outcome for youth and their families.

I’ve really worked hard in this community on building those bridges between parents and professionals and giving each one a perspective. I think that’s why we’re unique because we are professionals and we are parents. I can go to a parent and I can say, “I understand what you’re feeling, but this is why you need the professionals and this is what they can bring to you if you’ll just listen.” And then I go to the professionals and say, “Do you really know what this family goes through? And let me put you in their shoes for just a minute, and then can you treat them as part of the team?” This is what they need from you as a professional to bridge the gap. So I think that it’s an advantage to have the experience of being a professional and being a parent, and I think that’s helped in the community as a whole. I’m not known as a quiet one by any means around here, but I’ve also learned diplomacy and how you deal with the people to get the end result that you want.

Parent Support Specialist

I think it’s a fine, fine line that parent support walk between trying to be a staff, a parent and an advocate. The ones I’ve seen balance it well are able to see both sides of the fence. They’re able to put on the hat of being a professional and a staff person. They’re able to look at the big picture. They don’t get so caught up in this little moment in time or this little detail. And they can empathize and understand the parents’ perspective. They can see both sides of the fence and they tend to temper some of their enthusiasm.

Administrator

I think that you really go into it leaving your needs and your emotions at the door. You can be passionate and not be combative. That’s the way with parents, too. We can work together and we can be passionate for this, but we don’t have to be
combative. We don’t have to be oppositional. But how are we going to do this? A team, you know. How are WE going to do this with a child?

Parent Support Specialist

- **Professional Relationship Skills**

Effective parent support specialists possess a high level of professional relationship skills. This includes the ability to recognize the purpose of the helping relationship and how to encourage independence and interdependence. This skill development is challenging because parents and PSS share a common experience rearing a child or youth with SED and develop close bonds around these experiences. Personal characteristics such as a non-threatening approach, authenticity, and honesty were often noted as helpful characteristics when respondents illustrated examples of professional relationship skills.

> I was always told that when you come into a family’s life you’re working your way out. So I need to find every support I can for them to work myself out of their life. And I think that’s hard for all of us, because you do make relationships, not friends, you make relationships with people because every family that I work with dumps everything they have the minute I walk into the door. It’s just, when I said non-threatening, I’m not going to judge them, they know I’m not going to say why in the heck did you do that?

Parent Support Specialist

> If you in the beginning promise them honesty, then as your relationship goes, then you can always access honesty. And it’s a theme you hear from them all the time. I’ve been in the system a long time, they’ll say. Nobody was ever honest with me. And I think if you promise them honesty, then when those boundaries are permeated, then you can say now remember? I promised you honesty. And then you’re able to give them the feedback and then they’re able to assess. You have to promise honesty.

Parent Support Specialist

- **Skills Are Developed Over Time**

There is an evolution or process that PSS undergo to develop diplomacy and professional relationship skills. The process includes learning how to find an individual balance by setting limits and caring for themselves. For example, some PSS reported that when they first started providing services, they would be available to families whenever they called. As time went on, PSS learned that parents could learn to handle some situations without their support. Over time, some PSS reported that they came to realize the component that makes the PSS services so helpful to families—the experiences PSS bring as parents of children with SED—was also the component that could lead some PSS to be overzealous in their efforts to help the families. Participants reported that PSS must strike a delicate balance of holding onto their passion while calmly and diplomatically assisting parents to maneuver within the system. These diplomacy skills were developed with patience, time, training, trial and error, and
mentoring. In addition, successful PSS possess certain characteristics that make them especially effective. It is likely characteristics such as authenticity, patience, and persistence support the development of these crucial diplomacy skills.

I think it’s finding a balance is what it is, and I think that it’s a challenge to come in here and not get emotional, because you live this story. I think it’s training. I think that you come in here with all the experience and the knowledge and the passion like no other, because I know that myself and a lot of people come in that way because you just want to help somebody else not have to struggle the way that you have. And you bring that passion with you. It’s finding the balance and toning down that passion to be productive. That is the challenge, and finding that is trial and error. You come in here and you work 24/7. You say oh, I know what it’s like. I’m lucky to have a good family that helps me when my kids are in crisis, but these people don’t have anybody, and so I’m going to be there. Until you look around and you say well, wait a minute, my family’s slipping here because I’m so available to other families. And fighting that. I can remember a lot of training and working with my supervisor and her saying, you need to slow down. You need to take the phone off on the weekends and me arguing back with her because I have this passion for these parents. And then learning that you know what? One weekend I just didn’t have my phone and I had a family in a horrible crisis and they made it through without me. I didn’t think that was possible, but they did.

Parent Support Specialist

- Systems Navigation Skills and Aptitude

To be effective, parent support specialists need to know how to navigate local community resources or have the aptitude to learn quickly. Specifically, PSS must know the acronyms, funding issues, and how to refer and secure the start of needed services. Again, personal characteristics of persistence and high follow-through are illustrated in participants’ examples of how PSS help families navigate systems.

I call my parent support in a crisis and she’s right there on the ball and says, "This is who you need to call. Let me make a phone call." And then I call her and say, “Okay, this is what I found out.” And she leads me in the right way as to what to do. I’ve had her come to school meetings and educate the teachers and give them suggestions and give them help as to how to deal with my individual kids, because all 3 of them are different. So she’s had to come and tell them to try this and try that. Now the teachers come back to me and say that worked!

Parent

Parent support is knowledgeable. She seems to make it a point to try not to learn just about mental health services but services in general, and so if you ask her something in regards to that, if she doesn’t know, she’ll try to find out or confirm it, which is extremely helpful. It isn’t always just about mental health services. It may be going to intramural sports. It could be anything involving your child that would benefit them as a whole. Or if you’re having an issue getting them into intramural sports because of the therapy they’re in. Guess what? You have an advocate in your
corner that’s going to ask the questions right there with you. Why can’t my child participate? Those are really nice things to have.

Parent

If we present her with something that she don’t know the answer to, she usually tries to find us the information so we will know what it is, instead of the hearsay, somebody told me this, is it true? Within 2 or 3 weeks or her next visit or if it’s real pressing she’ll find it and call us and let us know.

Parent

When I think of the acronyms that you throw around in mental health, about the resources that we have to know, the court system and about IDEA laws? You know how much schooling you’d have to have to have that kind of cross-training? It would take forever to bring someone up to speed on these things. We know it because we have to. We learn it because we have to. We know the systems because we have to.

Parent Support Specialist Supervisor

- Skills Maintaining Professional Relationships & Being Assertive

Parent Support Specialists teach parents how to find their advocacy voice. At times PSS have to speak out on behalf of parents within their own agencies. Effective PSS are able to model for parents how to be assertive while maintaining good working relationships with other agency staff. Parents are appreciative of PSS efforts.

She was the one that got my son back into services. If it hadn’t been for her we probably would have waited another 2 or 3 months. It took her fighting within her own agency, which she did. And that’s why I’m just so comfortable with her, because she’s understanding and caring. She goes the extra mile whether that means that she’s going to get in trouble. That’s got to be hard to step into your own place and say hey, you’re messing up.

Parent

She works it until they tell her yes, to get what our kids need. Otherwise my kids would probably all be in a pine box. I’m not joking one bit. And so would I, had she not stepped in at the point that she did and got my kids the things that they needed.

Parent
There’s some behind the scenes advocating that goes on in a variety of ways. And sometimes we’re successful and other times we’re not. That doesn’t mean we don’t keep trying. There’s always the danger that a parent support specialist might get institutionalized into the system, but from my understanding, not from hearing what the parent support specialists have said, but from hearing outside, that the ones at this agency are very successful at staying distant enough from the institution to be able to serve that function. It is a very delicate balance because you have to work with these people and yet you have to fight them, and that’s very difficult.

Parent Support Specialist

Summary Study Question 2: What Personality Characteristics, Life Experience, and Skills Do Parent Support Specialists Bring to the Helping Process?

Parent support specialists bring a wide variety of backgrounds and individualized approaches to their work. The most commonly identified experiences PSS described were having a family member living with a mental illness or serious emotional disturbance. These unique attributes allow PSS to develop unique and powerful therapeutic relationships with parents. PSS need an eclectic approach to managing the therapeutic relationship that evolves from personal experience, training, and on the job learning. Effective PSS are viewed as engaging, non-threatening, honest, accessible, committed, persistent, purpose driven, passionate, and evolving. Furthermore, effective PSS possess well-developed diplomacy and professional relationship skills to manage therapeutic relationships with parents and work relationships with fellow providers. Effective PSS have the necessary skills to balance the advocacy nature of their work as employees of the CMHC. Effective PSS possess expert knowledge regarding navigating and accessing community resources.
PARENT SUPPORT SPECIALIST PROGRAMS

Study Question 3: What Are the Components of a Parent Support Program (Primary Roles and Functions That Parent Support Specialists Perform)?

This question was answered with qualitative data from all focus groups and interviews. In addition, the state mental health authority provided a list of suggested functions.

3.1 Parent Support Program Components

The primary roles and functions that emerged from the qualitative data were combined with the list of suggested functions provided by the state mental health authority. The resultant components of parent support programs from these two data sources are listed below.

- Advocates and informs parents about child/parent rights within the child’s school district.
- Educates and informs parents about federal and state regulations around school issues, including Individual Education Plans (IEPs).
- Attends IEP meetings or other school meetings with parents.
- Supports parents at meetings or events other than at school, such as going to court.
- Helps parents use techniques with their children at home such as role playing or something the therapist suggested they try.
- Helps parents cope with stress and manage their households, including things like setting priorities, paying bills, and taking care of themselves.
- Makes suggestions for managing children’s behaviors at home and elsewhere.
- Helps parents use what they learn in workshops or parenting classes with their children in the home.
- Tells parents what they can expect from other organizations such as SRS and the courts.
- Tells parents about things at the mental health center, such as services that are available and service providers.
- Serves as negotiator between parents and CMHC staff to resolve issues or differences that arise.
- Assists families with resources in the community.
- Helps families when children are having a crisis.
- Helps parents learn ways to prevent crises with their children.
- Holds family nights/parent support groups for parents.
- Provides support for whatever reason needed, such as listening and letting parents know they are not alone.
- Provides workshops on subjects such as childhood development and information about children’s diagnoses.
- Provides parenting classes.
- Talks with other service providers at the mental health center for the betterment of the child and/or family.
- Talks to others on parents’ behalf such as staff from school or other agencies.
- Helps parents better understand what other service providers tell them.
- Helps parents complete paperwork (e.g., CBCLs) for the waiver or government agencies.
- Supports and encourages parents to have a voice in their children’s case plans at the mental health center.
- Provides transportation for parents and/or their children to appointments or activities at the mental health center.

### 3.2 Frequencies of PSS Program Components Provided

On questionnaires, parent support specialists (PSS) were asked to indicate the primary roles and functions they perform from a list of selected program components. Those components with the numbers and percentages of PSS who offer each one are provided below. Almost all PSS advocated and informed parents about their rights within schools, attended IEP meetings or other school meetings, located community resources, and talked with other service providers at the CMHC. The least provided functions included presenting in the community and providing informational workshops.

**Primary Roles and Functions Performed by PSS:**

- Advocate and inform parents about child/parent rights within the child’s school district; \( n = 41 \) (97.6%).
- Attend Individual Education Plan (IEP) meetings or other school meetings with parents; \( n = 41 \) (97.6%).
- Locate community resources to help families meet various needs; \( n = 41 \) (97.6%).
- Talk with other service providers at the CMHC for the betterment of children and families; \( n = 40 \) (95.2%).
- Provide information to families about what services are available to them through the CMHC; \( n = 40 \) (95.2%).
- Educate and inform parents about federal and state regulations around school issues, which includes IEPs; \( n = 38 \) (90.5%).
- Serve as negotiator between parents and CMHC staff to resolve issues or differences that arise; \( n = 36 \) (85.7%).
- Hold family nights/parent support groups for parents; \( n = 34 \) (81.0%).
- Provide parenting classes or trainings; \( n = 31 \) (73.8%).
- Serve as a member of community organizations and do outreach for CMHC; \( n = 29 \) (69.0%).
- Provide informational workshops on subjects such as children’s diagnoses; \( n = 25 \) (59.5%).
- Present in the community on mental health issues; \( n = 18 \) (42.9%).

**Other functions written in by PSS on questionnaires include**

- Help family understand the mental health system and services available.
- Help family understand and fully participate in their child’s educational team.
- Serve as a sounding board, safe place to vent frustrations, and someone to talk to.
- Assist with parenting skills and problem solving in the home.
3.3 Curricula Utilized

On questionnaires, 30 (71.4%) of 42 parent support specialists offered the following parenting classes or training:

- Parenting With Love and Logic (used in 10 programs);
- 1, 2, 3 Magic (8 programs);
- Conscious Discipline (5 programs);
- Common Sense Parenting (4 programs);
- When Being a Good Parent Is Not Enough (4 programs);
- Visions for Tomorrow (3 programs);
- Basic Parenting (2 programs);
- The Nurtured Heart Approach (2 programs);
- The Total Transformation Program (2 programs); and
- In one of each of the following programs: Active Parenting, Active Parenting 1-2-3-4, Active Parenting for Teenagers, Boys Town Program, From Emotions to Advocacy, Los Ninos Bien Educados (The Well Educated Children), Parents Who Care, Parenting Wisely, Responsive Discipline, Strengthen Families, Surviving Your Adolescent, The Steps to Positive Discipline, and Winning at Parenting Without Beating Your Child.

3.4 Receptivity to Training

Parent support specialists were asked to respond to the statement, “Generally, parents are receptive to parenting classes or training I provide.” Of 37 PSS who responded to a scale from 1 to 5, with 1 indicative of never and 5 indicative of always, the mean score for this parental receptivity was 3.79. The PSS responses included the following:

- 5.4% (6) of PPS said parents are always receptive to training;
- 51.3% (20) of PPS said parents are often receptive to training;
- 30.8% (12) of PPS said parents are sometimes receptive to training; and
- 2.6% (1) of PPS said parents are rarely receptive to training;.
- No PSS said parents are never receptive to training.

Parent support specialists were asked to respond to the statement, “I have seen the parent training I provide help parents improve their parenting skills, which helps their children function better (e.g., behavior). Of 39 PSS who responded to a scale from 1 to 5, with 1 indicative of never and 5 indicative of always, the mean score was 3.85. The PSS responses included the following:

- 4 (10.3%) always see improvement;
- 25 (64.1%) often see improvement; and
- 10 (25.6%) sometimes see improvement.

Although 30 PSS said they provide parenting classes or trainings, 39 responded to the statement about parental receptivity to training and the statement about seeing improvement in parenting skills. One can only speculate about the reason for the discrepancies in these numbers. During site visits, PSS discussed visiting family homes to
assist with parenting and viewing videos with parents. Perhaps the 30 PSS were thinking in terms of formalized classes or training when completing questionnaires and some of the 39 PSS who provided ratings about receptivity and helpfulness were thinking in terms of less formalized parenting assistance (e.g., in family homes).

3.5 Summary of Primary Functions From Focus Group Data

In focus groups participants were asked, “What functions do parent support specialists perform that you see as most important?” Fourteen categories of functions emerged from the qualitative focus group data.

3.5.1 Providing Informational Support (91 Quotations)

This function entails providing specific information to parents regarding what they can expect from their own CMHC or other agencies (such child welfare and schools). This includes helping parents obtain the correct information to navigate the systems they encounter. The key to success appears to be the way PSS provide information to the parents. Parent support specialists take the next step to make sure families understand how to use the information or resources provided by going with families to access the resources or making sure the resources suggested are meeting the families’ needs.

I think it’s really important that you educate families on what the agency can do with them and can’t do, because a lot of the conflict arises when families expect something that can’t be given to them. And oftentimes other agencies tell families about services we can provide.

Parent Support Specialist

A consistent theme within the informational support is providing information to parents regarding the individual education laws and keeping parents informed regarding their rights.

One of my favorite memories of working with a fellow parent support….we went to a school meeting and it was me and the case manager, the parent, my fellow parent support, and the teacher. This was an IEP meeting and that’s all the school had there. And so the teacher had it all typed out, everything was perfect, perfect, perfect. She passed it to the mom and said now just sign here. And my coworker said, “No, I don’t think so.” And the mom stopped and it’s almost like the pen got on fire. The mom looked at my coworker as my coworker said, “No, we’re going to take this document home and go over it piece by piece.” This action saved this parent, because out of that meeting the parent was not going to get busing or anything she needed for her kid. The next week we went in there and there was 18 people around that table and my coworker was late, so I walked in there and I thought you can do this. And we did. We got everything. This is an important piece of documentation that you need for this kid.

Parent Support Specialist

Parent support specialists make sure families have the right information about a diagnosis or medications.
When we started my son on medicine she brought us a book about ADHD because they diagnosed him with ADHD and started him on medicine. At age 4, what are the ramifications of certain medicines on a 4 year old? And she doesn’t push medicines on you either. She’s not one that says yes, you’ve got to have medicine or anything. She’s never been that way. But she’s also not critical of you if you choose to go ahead. She’s very neutral.

Parent

Parent support specialists share information regarding how other families have solved different situations.

This is a situation where she has had so many families in similar situations and she knows how each family has solved these different things, so she’s got this wealth of experience that she can offer, and if you don’t use your PSS then you don’t get this information.

Parent

3.5.2 Providing Affirmation and Emotional Support (71 Quotations)

Parent support specialists validate the distress parents feel rearing a child with SED by listening to concerns and sometimes just sitting with families through difficult situations. In this process, PSS often coach on how to handle stress, support and identify parent’s strengths as well as provide feedback regarding what to do in the future. In summary, this component affirms the parent’s crucial role in their child’s life which in turn builds parent confidence and instills hope. Parents view PSS as the most credible resource for this type of support because they have been through a similar experience.

Just being able to talk to someone that understood what you were going through. You talk to other people and they just think you have a bad kid. But to be able to talk to someone that understood and had a child of their own was so helpful.

Parent

They give you confidence when no one else is telling you you’re doing a great job. So you can be proud of what you do and not feel that it’s overlooked. So you can keep going. They’re the one person I can call and scream at on the phone and say by the way, this is just a message and I’m sorry. Yeah. Sometimes you need to vent and there’s very few people around that will allow that.

Parent

One of our parents states that she receives moral support from her parent support worker. The parent support worker backs her up when she makes a decision on how she’s going to handle something. Parent support is there to back her up and reassure her and just give her support that she needs for her decisions.

Parent
I feel like I’m just a little bit saner after she leaves. Okay, I’m going to be okay. I’ll go through my really bad weeks where I’m just not even doing half as well as my child is doing. I’m having a really rough time like a lot of other parents. I really don’t think we would be as far as we are today with our child if she wasn’t involved right at the very beginning. That’s why I think family support is so important right at the very beginning, because parents are so lost. They’re going through all these emotions and if you don’t have somebody that you feel like is behind you, backing you up, it’s almost like you against everybody else. They kind of just expect you to know what this term means and what this therapy is for and this medical card is different than this medical card, but you just don’t.

Parent

Part of the time it’s just to be there as emotional support…In addition to that, it’s just whatever, if a parent is having a particularly difficult time then we can call and ask for some extra support from the parent support.

Administrator

According to direct service staff, this additional type of support is particularly helpful when families are new to services and during attempts at crisis prevention.

We have a new family that we were just discussing this morning where mom is just at her wit’s end. She’s ready to be done with that. She made the comment at a meeting yesterday that last weekend she was ready to leave dad and the kid both, because she’s just so frustrated with the whole household situation. We have a waiver and we’re going to be starting services. There’s going to be a lot of staff involved in keeping the family together, and it’s comforting to know that while there’s so many of us working with the kid, that we’ll have a parent support person who’s just there for mom and dad and help keep them together during the whole process where we’re trying to make changes with the kid and the family and the community and the schools. There’s so many other places where we need to work. It’s nice to know that there’s someone there just to provide support for mom and dad in the house.

Direct Service Staff

Crisis prevention… I have a mom that we’ve worked with together who at some times has said, “I just need a break.” I know we all have families like this where sometimes we think the parents probably know when they need a break, and if they can’t get it they might push the kid to blow, so that they’ll have to be screened and go to the crisis house or the hospital for the weekend so that they get their break. If that can be prevented just by being able to talk to a parent support person for an hour or two and vent, then that’s so much better.

Direct Service Staff

In a feedback presentation on preliminary findings regarding PSS primary functions, the large majority of PSS in attendance noted that the affirmation and emotional support are unique components that only the PSS are able to provide within their respective agencies.
3.5.3 Bridging the Gap Between Service Providers and Families (52 quotations)

Parent support specialists engage parents in the treatment process by facilitating development and application of realistic treatment goals. For example, PSS work with families and/or service providers to develop goals that better fit the situation.

You are constantly being bombarded with information from your case manager and your therapist and your school. Sometimes it’s overwhelming. I go to my parent support and ask her what she thinks. I’ll lay it out. In my mind it’s sometimes scrambled. So I come to you when I’m really confused. I’m like I don’t understand this. Help me. I’ll lay it out and you’re the one that helps me understand it. She’s the one that pushes me sometimes to even well, yeah, that’s a good plan and I heard that too, but why don’t we ask for this and this, too, to help get to the goal? And we could go to the goal if we go this way. This is a shortcut to the goal. So I’ve got somebody there thinking for me and with me.

Parent

In her role probably the most important feature of that has got to be her ability to credibly engage with the parents because of where she’s been and what she knows. There’s an empathetic relation that can take place which adds to her credibility, yet she brings to the table a balance of we understand the plight that you’re going through with a connection to the professional treatment that we’re offering. Sometimes that can feel kind of cold to families as you’re prescribing A, B, and C… Parent Support helps bridge the gap for both sides of the fence. She keeps us in touch and sensitive to things that we might not otherwise be aware of, and at the same time, again, brings some legitimacy regarding the treatment to the family and says yes, it doesn’t feel right….I wouldn’t say it’s a task, but it’s more of a role, is to be an intermediary.

Administrator

I think that’s the red flag, is helping the parents understand. When we feel like a family’s just really frustrated and they’re almost to the point of blaming the child or looking for anybody but the fact that it’s just nobody to blame, but they’re very angry and don’t really seem to know how to handle anything that happens. Case management at that point can only do so much and be there so much. Parent support can come in and help fill that gap and focus more on what the parents are needing to cope with what they have to deal with.

Direct Service Staff

I think in our program the parent support worker has to be somebody who has been successful in achieving a little bit of a balance, because there are times when she becomes an advocate for the parent, and she may come to my meeting and say hey, you really need to understand where this parent’s coming from. You need to be a little more understanding or a little more bending in what you’re doing. But there are also those times when she may have to go to a parent and say hey, I know this
is not easy. I’ve been there. But this is no time for you to be giving in. You’re going to have to be tough. You’re going to have to make some hard decisions. **I think a good parent support person can’t always be on the parent’s side or can’t always be on the professional’s side. She does have to kind of bridge that and keep some balance.**

Administrator

**3.5.4 Representing the Entire Family (25 Quotations)**

This function is closely related to the bridging function discussed above. Parent support specialists are often instrumental in keeping all the important information on the family known in situations where there is high turnover of case management staff and a possible communication or service lag between providers.

_I’ve had a few cases where the case management turnover has been very, very high, whereas the parent support worker has been really consistent, and that’s been very beneficial because the parent kind of starts to lose trust in case managers because they may have had 5 or 6, and so while they may not feel comfortable having to tell me everything, or wanting to have to tell their story to a 6th person, they have a parent support worker that’s been there with them through the whole time who can relate back to you if there’s something going on or the child in the family’s history versus the parent having to sit down and do it a 6th time. And that’s been beneficial. And a good support for the family._

Direct Service Staff

In addition, PSS assist with keeping youth in the home because PSS can share the entire families’ story with Child Welfare providers and help prevent out of home placements.

_One major benefit is our family support worker has always had full details on each adult, each child in our family, our home life, school life, and all the workers involved in our children’s lives. Therefore, she has been able to represent our case to the foster care contractor, the child welfare providers, the developmental disability organization, police, adoption agency, lawyers, and schools as a whole smooth combined unit. I have given our foster care social worker the name and number of parent support to answer their questions instead of five or six names and numbers of other workers who only know a small portion about our family._

Parent

_She knows the struggles that I’m dealing with him, so she’s always asking the whole circle. She understands I have a very stressful job, too. I just think she does the whole circle of making sure all aspects of your life is going okay, not just what is with that child, because she understands everything else comes into it._

Parent
3.5.5 Linking Families With Needed Resources (52 Quotations)

This component includes identifying and linking families with resources they need to maintain a stable home for their children or find some stability in their communities. Parent support specialists’ efforts may include locating resources such as food, money to pay utilities, transportation to appointments, and shelter.

**She knows all the resources that other workers won’t tell you.** You can go up to SRS and they say we don’t have any services to provide you. Call parent support, and she’s rattles off 10 places. I’m like why didn’t they tell me this? She knows everything that’s out there and they won’t tell you, but she will tell you. Then you’re able to make your problems smaller. You’re able to, instead of being in a big room like this you’re able to be back in your home.

*Parent*

That’s been a definite positive because I’ve had some **families that have transportation issues** and I’ve got a few parent support workers who have really stepped up to the plate and said I’ll go by and get mom and whoever else.

*Direct Service Staff*

They help with **finding resources for the parent to use to pay electricity bills** and provide their kids with Christmas gifts… The parent support is really good about finding community resources to help provide that stuff for them.

*Direct Service Staff*

A lot of times I will refer them when the parent is sharing with me that they’re having a hard time making their bills and this and that, and so I refer them to her because she knows different places where they can go and get assistance and help with stuff like that, which **a lot of times helps the family. When you don’t have that money problem or that stressor it helps the other problems, too.**

*Direct Service Staff*

Beyond just securing the resources, PSS become instrumental in ensuring these services are accessible and utilized. The personality characteristics of persistence and high follow-through were evident in participant illustrations of the linking function that parent support specialists perform.

**You helped me with a community that was hostile. The whole community was, I won’t say openly hostile, but not supportive of my situation. You helped me find ways of reaching out where I could get support.** You were able to listen to my situation and ask questions so that I could think. That, plus getting me connected with the community that was a little more tolerant. Seeing the kids as kids rather than as a problem. Huge!

*Parent speaking to a Parent Support Specialist*
You woke me up to think it’s not weak of me to ask for help. You actually showed me. I was burning myself up inside and becoming a zombie, literally. So you see, you gave me a life again. See how important you are? And I know a lot of other people, too, have said the same thing. We talk about you all the time.

Parent speaking to a Parent Support Specialist

3.5.6 Facilitating Peer Support (31 quotations)

Peer support is closely related to the linking function discussed above. Parent support specialists serve as a peer model that facilitates a connection with a peer support network of parents who are rearing children with SED. This connection reduces the isolation parents feel and begins to build a safe community for families to learn in and get support from.

I look forward to coming each week, because coming to support group is my out. They say you have to do things for yourself. What did you do for yourself this week? Well, I came here. This is what I choose to do, because this is where I find the support that I need. Not only do I gain education, but I know that I’m not the only one that’s dealing with a child that is not normal.

Parent

The acceptance in the group is the most wonderful thing in the world. After being in all these meetings where people are doing this, to have everybody going oh yeah. It’s so wonderful because so many times parents haven’t had any group.

Parent

Most agencies in the study conducted a parent group at regular intervals (most were monthly) and open to all parents who received services at the community mental health centers. In some of the more rural agencies, travel and transportation issues made regular meetings more difficult.

The peer support that happens with parent support is unique in that it is a parent-to-parent relationship regardless of employment status, role or location in the state. A reciprocal helping relationship is established among parents who share, network, learn from one another.

I was the first one hired. But I remember that when I was being asked about the position I said, “Yes, I’ll apply, but if I don’t get it I would love to have a parent support worker myself.” So I got the position and I found out when I really started seeing parents, that I actually had lots of parent support specialists. Now I see about 20 parent support specialists in my mind, because that’s about how many parents I see. They provide as much support to me as I do to them.

Parent Support Specialist
The PSS have a statewide meeting every other month that facilitates connection and sharing of ideas as well as trouble shooting about how to encourage family driven mental health services.

Then when we go to our state parent support meetings and we’re around, I don’t know how many there are in the State of Kansas now, parent support specialists, so when we’re in a roomful of them yes, we receive a lot of support that way.

Parent Support Specialist

3.5.7 Intervening and Preventing Crisis (46 Quotes)

Parent support specialists are instrumental in crisis prevention, intervention, and skill building situations. Families call PSS because they are accessible, provide practical coaching, and know the families’ history.

She is real supportive. I’ve called her day and night and she’d hear the kids in the background screaming and I’ll say okay, one just ran out the door. How long do I wait before I call 911? Or I’ve got one beating on me and the other one’s crying because he’s scared of the one that’s hitting us. So she says okay now, take a deep breath and calm down. It’s like you’re on a thin rope and you’re saying what do you do, and you don’t know in that moment of crisis whether to call 911 or let the kid rage or what. So I call her and she can calm me down and tell me which way to go.

Parent

In a crisis situation by the time you’re ready to call somebody you don’t have time to explain. You have a child you’re fixing to strangle. Your house is torn up. It’s in shreds. You’re pulling your hair out. I don’t have time to explain why this child is going to end up in a bottomless pit. I don’t have the time. And if you call somebody that knows, they’re like wait, don’t do that. I already know about the pit. Don’t do that.

Parent

Parents and direct service staff said PSS are effective in these situations because they are observant of warning signs and proactive about diverting crisis situations by empowering the parents.

There is a cycle just like that for the moms and the dads that I work with. Once you get to know these families and you know how the family works, you know when things are about to explode. One of my moms, she doesn’t smoke except when she’s getting stressed. If I go into their home and I see a pack of cigarettes laying there, I know. So I ask, “What’s going on? Let’s have a chat.” It’s 8:00 in the morning, there’s no food in the house and I’ll ask the parent what they have done nice for themselves today? “Well, this is too early.” They’ll say. We’ll meet and we’ll do breakfast and we’ll talk about it. By the time that’s done mom has gotten out, she’s gotten in the sunshine, she’s breathing, and I had to remind her to breathe.
She says, “You did it to me again, didn’t you? Did what? I was hungry.” I just kind of minimize my role and empower them, because that’s what it’s all about. They’ve got it in them. I believe in my parents.

Parent Support Specialist

3.5.8 Helping Parents Find a Solution (37 Quotes)

Multiple groups of parents talked about how PSS help find workable solutions in stressful situations. Examples given included 1) helping parents to answer their own questions or try something a little bit different, 2) giving parents hands-on activities to promote emotional health, 3) helping parents see the positive things about their children, 4) identifying and linking families with trainings that would be useful, and 5) helping parents through group brainstorming activities.

Parent support specialists get parents to try something different.

She models it to the parents so they can see yeah, if I do try something a little bit different then I’m going to get different results. Because one of the things she always says is if you’re going to keep doing what you’re doing, you’re going to keep getting what you’re getting. It’s a solution-focused type thing.

Direct Service Staff

Parent support specialists provide hands-on activities to promote emotional health.

I’ll have them do an ecomap and show them how to do that to show where your stresses are coming from…. Some of them go, “wow, I didn’t realize there was so much stress.” “Where is your stress coming from? Where is your energy coming and going?” And you let them see it, because that’s our picture. And I have them come back with their ecomaps and ask, “Where are your supports, where’s your best energy coming from? Make that your focus when you have a crisis; go to that person.” And they’ve come back and had some really good successes.

Parent Support Specialist

Parent support specialists help parents see the positive things about their children.

With some of the kids that have really bad behavior she’s been really good for those parents helping them find the good things in their kids. Then it helps the whole entire process go a lot better with their kids.

Direct Service Staff

Parent support specialists help parents get to needed trainings.

Parent support is going to the conference in Topeka and they’ve arranged it so my wife can go with our parent support. Stuff like that, so she won’t have to miss out because I’ve got to work, because I’m her transportation and she does not drive. So that’s an awesome thing that they’re still able to do for that. That is very helpful. She
helps us out, suggestions around what else we can do different and things like that all the time.

Parent

Parent support specialists facilitate group brainstorming activities.

We got together with the group and we had the group of parents brainstorm on family activities we could do together and put it on the board and they ate supper and made coupon books for each one of the children in their home to do activities with. The goal was to cash one in a month with their kid, to do an activity with them.

Parent

3.5.9 Providing Trainings (21 Quotations)

Parent support specialists also provide parenting classes. The trainings mentioned are listed below.

- Love and Logic (2 agencies).
- 123 Magic (1 agency).
- Life Skills Training (1 agency).
- Parenting Education-General Tips (1 agency).
- Group for parents of children with Asperger’s Syndrome (1 agency).
- Group for parents of children with Bipolar Disorder (1 agency).

3.5.10 Assisting With Macro-Level Interventions (13 Quotations)

Parent support specialists interact in many ways in the community including serving on interagency coalitions representing parent perspectives; providing university sponsored training opportunities; assisting parents with lobbying efforts; and carrying out presentations for other organizations.

One of the important things that parent support does every year, she gets a group of parents together and she takes them up to Topeka to meet with the lawmakers and talk to them one-on-one about why they benefit from mental health services. I know that's not something that we’re involved in. It makes a great difference.

Administrator
Summary Study Question 3: What Are the Components of a Parent Support Program (Primary Roles and Functions That Parent Support Specialists Perform)?

Survey and focus group findings indicate that the primary functions provided the most were 1) providing informational support regarding children’s rights in the schools, 2) bridging the gap between families and institutions they come into contact with, 3) establishing peer support networks, 4) locating and assuring family access to community resources, 5) training parents in specific parenting techniques, and 6) providing macro-level community advocacy and education.

Focus group respondents identified two primary functions as the most important functions PSS provide: 1) affirmation and emotional support and 2) crisis intervention and prevention. The unique life experience PSS have as a parent or family member brings instant credibility to the helping alliance. According to the PSS participants in a feedback meeting on preliminary findings, this primary function is a unique role that only PSS can fulfill. Focus group participants strongly conveyed how PSS are instrumental in crisis prevention and intervention because they are easily accessible and provide practical coaching to parents. Furthermore, based on their own experiences, PSS understand how important it is to be accessible and available to help families when they ask for help. The affirmation and emotional support PSS provide can be particularly helpful to parents in diverting potential crisis situations as well as when families are new to community based services.
Study Question 4: How Do Parents Gain Access to Parent Support Services?

In addition to parent questionnaires and PSS questionnaires, this question was answered with qualitative data from focus groups with parents and direct service staff and interviews with administrative staff.

4.1 Referral Sources for Parent Support Services

On parent questionnaires, parents were asked who suggested parent support services to them. Of 144 parents who responded,

- 70 (48.6%) were referred by case managers;
- 35 (24.3%) were referred by therapists;
- 19 (13.2%) were referred when starting CBS;
- 1 (0.7%) was referred by school personnel; and
- 19 (13.2%) were referred by other child serving agencies or self referral.

Focus group findings indicated that families also get referred from community agencies, schools, and other parenting groups. In two agencies, school staff called PSS directly to ask for assistance with specific situations. In addition, sometimes parents hear about services from other parents and request the service.

4.2 Referral Process

Parent support specialists were asked on questionnaires, “On average, approximately how long after children start receiving community based services were parents referred to you?”

Of 41 PSS who responded, 12 (29.3%) indicated the referral varied depending upon family need and providers’ perception of family need. This finding was validated by four agencies in focus groups. Six (14.6%) said they did not know. Time frames reported for the initial referral to PSS after intake to other CBS include the following:

- 7 (17.1%) in 1-2 weeks;
- 9 (22%) in 1-6 weeks;
- 5 (12.2%) in 2-6 months; and
- 2 (4.9%) in 6-9 months.

In focus groups, agencies reported different ways of referring to PSS service; most parents (four CMHCs) were referred to PSS after intake to other CBS. Two agencies referred parents to PSS services at intake.

Some providers reported that PSS services were difficult to access after the initial referrals due to high PSS caseloads and inconsistent communication between PSS and treatment team members. One agency was working toward systematizing the PSS intake process to improve continuity of PSS services after the initial referral.
4.3 Benefits of Earlier Referrals

On questionnaires, parents were asked to rate their agreement with the statement, “It would have been helpful to me and my family to have received parent support services sooner than we did.” Of 125 parents who responded to a scale from 1 to 4, with 1 indicative of strong disagreement and 4 indicative of strong agreement, the mean score for this item was 3.5. The parent responses included the following:

- 78 (62.4%) strongly agreed that earlier PSS services would have been helpful;
- 33 (26.4%) agreed that earlier PSS services would have been helpful;
- 12 (9.6%) disagreed that earlier PSS services would have been helpful; and
- 2 (1.6%) strongly disagreed that earlier PSS services would have been helpful.

On questionnaires, parent support specialists were asked to respond to the statement, “I could more effectively help parents if they were referred to me sooner than they are currently referred.” Of 38 PSS who responded to a scale from 1 to 5, with 1 indicative of never and 5 indicative of always, the mean score on this item was 3.76. The PSS responses included the following:

- 10 (26.3%) said earlier referrals would always be more effective;
- 10 (26.3%) said earlier referrals would often be more effective;
- 17 (40.5%) said earlier referrals would sometimes be more effective; and
- 1 (2.4%) said earlier referrals would rarely be more effective.

In focus groups, 3 parent groups out of 8 said they would have liked to know about PSS services sooner. Many parents noted that it would have been helpful to learn of the service upon the initial evaluation for services or in time to prevent a crisis.

There’s something to be said for parent support specialists coming in earlier. If a parent support specialist had come in a lot earlier…it took 2 years to get an intake. If I’d had a parent support specialist earlier I may still be married. I may still have a whole different life because my ex was in denial until actually after the divorce. He was still in denial until he decided to get some help himself. He wouldn’t trust anybody and if things had come in faster, I bet things would be a lot different. Maybe we still would be divorced, because who knows. But that’s a really good point. Just recently I’ve been going around to therapists again and telling them if they have somebody that’s coming in early, get parent support in there as quick as possible.

Parent

4.4 Family Situation When PSS Services Begin

On questionnaires, the majority of PSS reported families are often isolated, under stress, in crisis, or having difficulty with parenting when PSS work begins. Some said work begins when families need a high level of support. A few PSS said they initiated work when there was a need for additional resources and assistance connecting with resources.
4.4.1 Youth at Risk of Out of Home Placement

In 8 focus groups, participants reported that when PSS services begin, parents are overwhelmed and need more tools to help manage their children in the home. In addition, youth are at risk of out of home placement and typically have accessed other community based services first.

*Parent support we also reserve for our highest needs kids and families. We don’t have it for everybody. It’s always those really, really high needs ones. So it’s often also when there is need to maneuver our agencies and systems more extensively than what case managers generally do. Case managers do that too, but it’s more of you really need a lot of energy focused on parent and school and it’s very time consuming.*

**Administrative Staff**

I have one example. Actually, I have 2. I have a father that the kids lived in another city with their mom and she died and it was pretty bad and long. She had a brain disorder. They watched their mother die, then they got sent down here with their father who’s a military person and the kids have just hit the bottom as far as school goes, and everything, and he doesn’t know how to father them. He’s never been a father before. That’s one person I sent to parent support. Now I have another one that the daughter missed 64 days in the 7th grade. She’s a truancy problem and the mother just got her back. She hadn’t had her. She’s lived with her grandmother. She enables her to stay home. And I can’t get her to realize that this is a real problem and you’re going to end up in the court system. And that’s another one I sent to parent support. That’s the examples of the times I’ve sent them.

**Direct Service Staff**

4.4.2 Families’ Need for Intensive Supports in the School System

My son has had an IEP for 3 or 4 years for major depressive disorder, and I think along with that, though not officially diagnosed, a little bit of oppositional defiance disorder. We’d been having just a lot of problems with the school and he had been hospitalized with depression, a lot of problems with medication management, and I was running into a brick wall because the IEP is supposed to provide certain accommodations, and it really wasn’t, because every time we identified something that would work for him, they would say well, we don’t have the resources to do that, so we don’t have to do it. I think that’s about the time we engaged with the mental health center and really started getting some parent support, attendance at IEP meetings, and that’s been a major Godsend.

*Parent*
4.4.3 Court Ordered Treatment for Parents

In one CMCH, services are reported to be effective with parents who have been court ordered to treatment because they reduce isolation that parents feel.

I was very skeptical. I was court ordered to do everything…I did not want to come because I said I don’t have a mental illness. I was refusing services. I was just fighting everything because I was so angry at the system and I had my blinders up and my boxing gloves on. I was very vengeful, very hateful. When I got here, to the mental health center, it was not just me. There was a lot of parents. When you’re in parent support classes, you bond with other parents and families and you become friends. You support one another, and it takes a lot of it off the shoulders of the parent support worker, because we can depend on one another. It’s brought our self-esteem up. It’s opened our eyes and made us more knowledgeable to the things that are out there. There was nothing really wrong with my son before he was placed in the system. When he came out he was a mess, and he still is a mess, but he’s not as bad as he was, because calming down and using common sense and listening to what I was told with the guidance through my parent support worker and everything else, a lot has been done. He is an excellent child. He’s an excellent student. The important thing is he’s at home. And I’ve got nothing but praise for the people here at the mental health center because they have done so much and we’ve been through so much together.

Parent

4.5 Access to Parent Support Services and the HCBS-SED Waiver

Direct service staff indicated that parents learn about the service when the waiver paperwork is initiated. At one agency, parent support was only available to families on the waiver. In another agency, PSS services are encouraged more to families who are on the waiver.

I offer every one of my parents parent support. We’re required to offer everyone who is on the waiver parent support and document that. I remind the parents who have refused parent support when they are having problems with their children. I remind them that there is parent support, and that’s how I get a lot of my parents involved with parent support, is by constantly reminding them of the resource.

Direct Service Staff

In one agency, providers reported that families who were not on the HCBS-SED Waiver had a more intense need for support. These families were often coping with the effects of poverty and receiving general Medicaid assistance. The PSS services provided included securing resources to meet families’ basic needs.

The lower income families benefit more from a lot of parent support. And some housing issues that they know about like that. Some of them have been through it, so they can give them more than what I can. It seems like the kids that we have on the waiver almost always don’t need as much parent support as the kids that we
don’t have on waiver. It’s a pretty drastic difference in terms of needs. This one particular kid that we have on the waiver, he’s gotten some parent support hours, but he really doesn’t need them as much as some of our other kids, because his mom has signed him up for hockey and he’s doing special music group, because she can provide the means for him to do all those things, which is helping him with his community involvement and social skills and helps her because he’s out of the house and she has time to herself. But you take a family that isn’t that fortunate and they’re really struggling.

Direct Service Staff

Summary Study Question 4: How Do Parents Gain Access to Parent Support Services?

Questionnaire and focus group data support that the majority of families were already in CMHC services when they were referred to PSS services. The time frame for referral varied from upon initial intake to years after treatment had started. Factors that affected referral included family need and when treatment providers (case manager or therapist) felt more support was needed. Regarding when PSS work begins, the majority of PSS reported that families were isolated, under stress, in crisis, or having difficulty with parenting. A few reported initiating work with families when additional community resources were needed. In focus groups, administrators conveyed that PSS services were reserved for families with the highest needs due to the limited number of PSS staff available to provide the services. Overall, parents said they would have liked to be referred sooner. PSS also concluded that earlier referral would help to prevent crises and the intense level of support PSS must provide when families have reached a crisis state.
Study Question 5: What Populations Are Served by Parent Support Specialists?

In addition to data from PSS questionnaires, this question was answered with qualitative data from focus groups with direct service staff and parents and interviews with administrative staff.

5.1 Strengths of Families Served

On questionnaires, PSS most often described the population of families they serve as independent, self-reliant, receptive, and looking for assistance.

5.2 Specific Family Situations

In focus groups, PSS participants repeatedly mentioned that PSS mainly serve families with one or more of the following characteristics: single parent families, families dealing with poverty, families with youth in state custody, and parents with a developmental disability or a psychiatric diagnosis.

5.2.1 Single Parent Families (5 agencies)

Single parents are over-represented in the program. So there’s a lot of vulnerability there, and one of the things that some of the kids struggle with, even at a younger age than you’d expect, even at maybe 10 years old or something, we have children who are very concerned about their parent, a lot of single moms, and if a mom has a health problem or a legal problem or anything else, the child is really feeling like I have to help take care of this. And when there’s somebody else [PSS] stepping in and helping to support the parent, then that takes some of that burden off of them, where they may be allowed a little more to just be a kid and focus on their own issues.

Administrator

5.2.2 Families Dealing With Poverty (3 agencies)

I’ve got a kid now that there’s 4 kids in the home and mom lives by herself. I mean the only person that lives there is mom and she doesn’t work because she’s got disabilities as well, so of course with 4 kids you’ve got to find a way to feed them and pay all your bills and everything on top of that, so parent support is able to step in and help pay a little bit on the utility bills and that sort of thing, and maybe go in and help the parents budget their monthly finances so that they have enough money to cover everything.

Direct Service Staff

5.2.3 Families Dealing With Court Issues (2 agencies)

For me I would say probably it was a court issue pertaining to my son. At that time the specialist was very, very, very helpful and the family was able to get through this.
One more time we have to go to court, but my son will turn 18. It’s been a rough one, but because of the people here at the mental health center and all the programs and people just giving my family moral support, we were able to get through this, and I really appreciate it. They’re really professional.

Parent

5.2.4 Families With Youth Returning Home From State Custody (2 agencies)

My son was just returning to my custody when I started getting parent support. It really helps just to be at home. My brother passed away about a month after my son came home. It helps a lot dealing with that.

Parent

5.2.5 Parents With a Developmental Disabilities or a Psychiatric Diagnosis (2 agencies)

One example given was a mother with a developmental disability diagnosis was receiving parent support while her children were going through the adoption process.

5.3 Families of Hispanic or Immigrant Origin

I’ve read in some of the parent support brochures that they should be the same race as the individual they’re assisting, which I think is a big thing here in this region of Kansas because we do have such a large Hispanic population. Our families benefit greatly from that aspect.

Supervisor

Summary Study Question 5: What Populations Are Served by Parent Support Specialists?

In focus groups, participants repeatedly mentioned that PSS mainly serve families with one or more of the following characteristics: single parent families, families dealing with poverty, families with youth in state custody, and parents with a developmental disability or a psychiatric diagnosis. Families of Hispanic or immigrant origin were also mentioned as a population that PSS serve.
ADMINISTRATION OF PARENT SUPPORT PROGRAMS

Study Question 6: How Do the Primary Roles and Functions Parent Support Specialists Perform Differ From Those Performed by Case Managers?

In addition to parent support specialist (PSS) questionnaires, this question was answered with qualitative data from focus groups with parents, direct service staff and interviews with clinical staff providing supervision for PSS.

6.1 Area of Focus

Parent support specialists’ focus is on parents, and case managers’ focus is on the children. On questionnaires, almost all PSS who responded believe they work more with the parents in order to benefit the children and case managers work more with the children assisting to manage the treatment plan. In general, PSS are focused on the parents, helping them to obtain whatever is needed to be available to their children.

The family service worker or parent support worker is very focused on just kind of the parent aspect and helping the parents with building skills or support, whatever they need to help with their child, and typically the parents need a lot of support and a lot of skill building that is pretty time-intensive, and so having a person that’s just dedicated to that is extremely helpful, whereas a case manager might not have time to get the support or work with the parents enough for the time that they need or deserve.

Direct Service Staff

6.2 Parent Support Specialists Approach

Parent support specialists approach mental health service delivery to families with the perspective of “someone who has been there.” A unique relationship develops between PSS and parents.

PSS brings more of a parent perspective because she’s a parent of children and a parent of a child who has had an illness, and so she brings a little different flavor to the beginning of the relationship than when Case Managers go in and say we’re from the mental health center.

Direct Service Staff

I see my role as different, though, because I approach the work from the perspective of someone who has “been there.” I may assist families in ways that identify needs of the family different from the case manager, which can lead to conflict between case manager and myself.

Parent Support Specialist
6.3 Teamwork

Though the approach of each provider is different, CM and PSS may be working on the same goal and thus tasks may be similar. According to participants, regular communication and teamwork to accomplish the treatment goals are important.

I think a lot of times parent support and case manager’s roles kind of cover each other. If PSS knows that we’re working on organizational skills or whatever it is, if she’s in the house and has an appointment with the parent she might sit there and kind of hey, you and the CM are talking about this. She’ll remind the kids to do certain things. I know, too, and I know the parents’ goals, I might say hey, you know. We kind of remind each other. Whoever’s in the house at the time might take the initiative and remind the kids of hey, you know you guys are working on this. Or how are you doing on your grades? She keeps up on that too, and we keep up on her end too.

Direct Service Staff

When I’ve seen treatment be a really good thing is when there’s really good communication between the case manager and a parent support worker so they’re not taking the family in different directions. They are both working in conjunction giving the family similar sorts of advice and guidance, and that they’re working together, so it isn’t that they’re competing. That they’re more supporting of each other.

Administrator

In feedback PSS stressed the importance of using teamwork in treatment planning.

Good teams understand each other and just do whatever it takes for families. That’s what it should be about, the families. And there are little bits to pull from this report. And what we find here is that people don’t understand their roles and some of them define it too much to the point where they separate. They may say, “that’s not my role. That’s your role and you stay out of my role.” And if something was going to come across that, I would think it would be important to get to people to understand how we work together. What our roles are and then now we can bridge that gap.
Summary Study Question 6: How Do the Primary Roles and Functions That Parent Support Specialists Perform Differ From Those Performed by Case Managers?

The primary functions differed due to the focus and approach of PSS. Parent support specialists’ focus is on the parents. Parent support specialists approach mental health service delivery to families from the perspective of “someone who has been there.” Case managers’ functions focus on assisting the parents to manage their children’s treatment. Though the approach of each provider is different, CM and PSS may both be working on the same goals and performing similar tasks. According to participants, specific tasks were best defined when teams were communicating regularly.
Study Question 7: What Training and Supervision Do Parent Support Specialists Receive?

In addition to PSS questionnaires, this question was answered with qualitative data from interviews with persons providing supervision for PSS and the focus group of PSS.

A parent advocacy group has historically provided PSS training. Although a new provider commenced training in the summer of 2006, the advocacy group was providing training during the data-collection period. The training consisted of 2 days of wraparound training and 2 days of Individuals with Disabilities Education Act Law (IDEA) training.

7.1 Training

7.1.1 Adequacy of Training

On questionnaires, PSS were asked to describe their agreement with the statement, “The training I received from Keys for Networking adequately prepared me for my position.” Of 38 parent support specialists who responded to a scale from 1 to 5, with 1 indicative of strong disagreement and 5 indicative of strong agreement, the mean on this item was 2.82. The PSS responses included the following:

- 1 (2.6%) strongly agreed that the PSS training provided was adequate;
- 8 (21.1%) agreed that the PSS training provided was adequate;
- 18 (47.4%) were neutral about the PSS training provided being adequate;
- 5 (13.2%) disagreed that the PSS training provided was adequate; and
- 6 (15.8%) strongly disagreed that the PSS training provided was adequate.

In focus groups, administrators and supervisors felt the training fell short in helping to establish diplomacy skills to prepare PSS to promote more collaborative rather than adversarial relationships in their communities. Respondents said the training needed to focus more the specific roles and responsibilities of PSS within a community mental health center.

We receive feedback that the training made it difficult for our parent support workers in that it presented ideas in a way that actually set the parent support workers up to be conflictual with the staff. Previous parent support workers may have had difficulties with that.

 Supervisor

I’ve seen the training that’s wonderful training, but I think the advocacy agency comes from a different background than what we do… I think training for parent support workers or case managers, the thing they have to understand is that we come from mental health center and our people aren’t mandated to come here. Their kids are diagnosed with a SED and we give them all the information that we can, but we don’t like to battle schools. We like to give the parents the information they need. Sometimes with my PSS she’ll say well, Keys says it has to be this way and Keys says it has to be that way. Probably that is true for Keys, but sometimes we do
things just a little bit different. We just don't make the stand maybe like the advocacy agency does.

Supervisor

7.1.2 Suggestions for Improvement of Training

Suggestions for improving training offered by PSS on questionnaires included the following:

More or additional information that addresses,

- understanding state and federal laws that impact children with special needs;
- developing collaborations with other community agencies (not just schools);
- working more one-on-one with parents;
- providing parenting training;
- learning hands on practices for crisis situations;
- focusing on practical aspects of the job such as paperwork, effective goal writing, team work, collaboration, and resource development; and
- training on being a PSS as an employee of a CMHC.

Structure of the training could be improved by

- having the training be done by a PSS (strongest theme);
- bringing in more parents and children; and
- providing more trainings with less information per training.

7.1.3 Other Trainings Mentioned

In focus groups, participants mentioned the trainings and workshops listed below for PSS.

- Case Management training and Attendant Care Online Training provided by the Kid’s Training Team. The Kid’s Training Team is a statewide collaborative effort of the Kansas Department of Social Rehabilitation Services (SRS), Wichita State University (WSU), the Training Advisory Group (TAG), and Title XIX Medicaid Programs (5 agencies).
- Families Together training on IDEA Law and Rights (2 agencies).
- Internal workshops mentioned included topics on
  - specific conditions (autism spectrum disorders, attachment and bipolar) and
  - talks on discipline and child rearing (Love and Logic, Love and Limits, Conscious Discipline and Family to Family Education).
7.2 Supervision

7.2.1 Supervisors

On questionnaires, PSS were requested to identify the titles of persons providing their supervision. Persons listed included the following individuals:

- CBS Supervisors;
- CBS Directors;
- Clinical Director;
- CBS Supervisor;
- Clinical Coordinator;
- Therapists;
- Director of Parent Support Program;
- Waiver/Foster Care Coordinator;
- SED Waiver Coordinator;
- Team Leader; and
- CSS Director.

In focus groups, supervisors identified were

- parent support workers (2 agencies) and
- qualified mental health professionals such as a social workers or psychologist (6 agencies).

Professional experiences of supervisors were varied and included

- state and county leadership;
- child welfare;
- sex offender treatment; and
- private clinical practice.

7.2.2 Frequency of Supervision

On questionnaires, 42 PSS reported the following regarding frequency of supervision:

- 3 (7.1%) meet with their supervisors twice weekly;
- 22 (52.4%) meet with their supervisors weekly;
- 8 (19.0%) meet with their supervisors biweekly;
- 6 (14.3%) meet with their supervisors monthly; and
- 3 (7.1%) reported their supervision occurred on an “as needed” basis.

In focus groups, frequency of supervision varied.

- 4 agencies meet weekly for staff meetings;
- 1 agency meets every couple months for individual supervision;
- 2 agencies meet weekly for individual supervision for approximately an hour;
- 1 agency meets weekly (and more as needed) for individual supervision; and
7.2.3 Accessibility and Availability of Supervisors

Parent support specialists were asked to respond to the statement, “The person who provides my supervision is accessible and available.” Of 42 PSS who responded to a scale from 1 to 5, with 1 indicative of never and 5 indicative of always, the mean score on this item was 4.24. The PSS responses included the following:

- 40.5% (17) of supervisors are always accessible and available;
- 42.9% (18) of supervisors are often accessible and available; and
- 16.7% (7) of supervisors are sometimes accessible and available.

In focus groups, participants indicated that most supervisors were accessible when needed (5 agencies).

*I have an open door policy and so they’ll pretty much come in here and sit down and visit with me on cases and keep me posted of any problems with community providers, if they’re having trouble getting a provider to return their call or whatever, and they’ve gone up the chain and they haven’t received any responses and they’re frustrated, parents are frustrated, then they come and they talk to me at any time. It’s pretty open around here although we don’t have formal supervision as often as other people do, because our caseloads are just too high. You’re running 50 to 80 cases to sit around and talk about all of them every single week, it’s just too much. We have a different way of viewing it. We do it through staff meetings. We do it through open door.*

_PSS Supervisor_

7.2.4 Role of Supervision for Parent Support Specialists

In focus groups, participants conveyed that supervision was the place where PSS refined the understanding of the balancing act and of the different roles they were required to manage. Supervisors provided the mentoring and supervision needed to achieve the balance between agencies’ agendas and family needs (6 agencies).

*You have to understand that you become an advocate, but you also have to learn that it’s a very fine line that you’re walking on. It’s like a little tightrope because you are representing the MHC, but you’re also advocating for your client. At times you*
can be seen as adversarial within your own agencies. It’s a very tricky balance and the person has to be able to take supervision, to take direction so that I can make sure that she understands this tightrope that she’s walking on, because I don’t want her to fall. They have to understand that it’s a balancing act that you have to do. You’re needing to appease two different audiences at times. They have to be able to have the ability to understand that and not feel like I’m going to be an advocate for my client no matter what. Well, that’s not the world that we live in. You’re still employed through a mental health center and you still have expectations that the employer’s going to have, that the agency’s going to have, and you can do both. She’s learned how to do both. But it takes awhile to be able to do that.

Supervisor

In addition, supervision was the time when possible boundary issues with families was often discussed and worked through (8 agencies).

It’s a very different position and it’s a tough one to negotiate, especially for an individual who’s not as trained and so there’s a lot of supervision that goes along and a lot of coaching, understanding the treatment side and the boundary side because you might hear tonight a parent saying oh, she’s my best friend. But the PSS has to know how to negotiate that and how to be very clear about yes, I’m here as a support but I’m not your best friend. It’s a little harder to understand those boundaries.

Supervisor

Sometimes there can be a fine line of dependency that exists and gets created in that relationship that cannot be optimally healthy. That’s, I think, part of where our supervision comes in and feedback and awareness. Boundaries need to be a part of training and what that looks like and understanding family systems and your role.

Supervisor

Parent support specialists appreciated a **trusting and open** working relationship with their supervisors. In addition, the effects of working in this culture impact the PSS’s relationships with parents (4 agencies).

It is a very delicate balance because you have to work with these people and yet you have to fight them, and that’s very difficult….I think it comes from the program director allowing us a great deal of latitude. She trusts us. That’s big. It’s very big. There are times when I’ve gone in without you and I’ve said I don’t like what’s going on here with this family. Here’s my take on it. And it’s been real beneficial to me and also I think there have been some things that have shifted and made services available.

Parent Support Specialist
7.2.5 Suggestions for Improving Supervision

Suggestions offered on questionnaires for improving supervision provided by PSS included the following:

- have the supervisor detail how to perform the specific expectations of PSS role (e.g. set up monthly meetings, arrange family nights, clarify PSS role from CM role);
- provide guidance and training to the administrators of PSS services regarding the integration of the PSS role within the CMHC, (e.g. PSS role on the treatment team, and establish the importance of a team approach);
- provide individualized and accessible supervision for PSS; and
- hold regular team meetings led by supervisors.

Feedback groups suggested addressing the PSS role in supervisory training.

**Summary Study Question 7: What Training and Supervision Do Parent Support Specialists Receive?**

Findings from focus groups and questionnaires support that training was not adequate to meet the needs of PSS in their professional roles as employees of a CMHC. Specifically, the training needed to address the development of diplomacy skills to manage therapeutic relationships and the delicate balance between PSS roles and responsibilities as employees of a CMHC. All groups reported that the training would be more effective if provided by PSS who were employees of a CMHC.

The majority of supervision was provided by an administrator or a clinician. Most PSS received supervision at least weekly and experienced their supervisors as accessible and available. The majority of PSS said supervision meets their needs. Supervision is utilized for refining skills to manage the therapeutic relationships with parents as well as finding a balance between advocacy and employee roles. Of the PSS responding to the survey, 23% (10) said supervision sometimes or rarely meets their needs. Suggestions for improving supervision included providing supervisors with knowledge about what PSS may experience transitioning from a consumer to a provider role and how to help PSS integrate into the treatment teams.
Study Question 8: What Might Be the Benefits and Consequences of Parent Support Specialists Pursuing Additional Education and Professional Credentialing?

This question was answered with qualitative data from interviews with administrative staff and persons providing supervision for PSS and a focus group of PSS.

8.1 Benefits

Most participants in the study thought that professional credentialing would not make PSS more effective. Effectiveness is based on other factors such as personality characteristics, unique life experiences, and skills developed on the job (4 direct service staff groups and 2 administrators).

However, all direct service staff and PSS felt like ongoing training of some sort was a good idea.

Two groups thought credentialing would be beneficial for PSS going into court rooms to lend more credibility when called to testify. Another group then said most of the work PSS do is not in the court room but in the halls with families. One stakeholder said credentialing would help when PSS begin work with new parents.

A professional credentialing program would provide another venue, beyond supervision, to teach about maintaining boundaries, family dynamics/behavior, and alliances. Parent support specialists would then have an orientation and frame of reference for the context in which they will be supporting parents.

Three groups thought credentialing would be beneficial to establish a standard of work performance and a higher rate of pay for PSS.

There were specific areas stakeholders identified that would be beneficial to include in ongoing training or a credentialing program. One group thought that training on mental health diagnosis would be beneficial to expand PSS perspectives on diagnosis. Another group thought that ongoing training on education laws would be beneficial.

Feedback groups of PSS raised the question, “Why do we have to be credentialed? We are parents already. We go through the training to be PSS.”

8.2 Consequences

Two agencies said, if credentialing is a requirement to be hired, agencies might lose good candidates with the aptitude to provide effective parent support. Credentialing would be better to be pursued once hired. One agency felt a degree was essential to do parent support work.
Summary Study Question 8: What Might Be the Benefits and Consequences of Parent Support Specialists Pursuing Additional Education and Professional Credentialing?

Credentialing could help establish parent support as a vocation, increase pay, and establish standards of work performance. Credentialing may influence PSS credibility in court situations and when beginning work with new parents. In addition, credentialing would provide another venue to refine PSS learning about managing the therapeutic relationships with parents, mental health diagnosis, and the how to provide the other primary functions. Participants cautioned against losing sight of what families say makes PSS effective, which is their ability to provide parents with hope that life will get better based on PSS’ abilities to share their personal experiences in a meaningful way.
Study Question 9: What Are the Dynamics Surrounding Staffing of Parent Support Specialist Positions?

In addition to data from the PSS questionnaires, this question was answered with qualitative data from interviews with administrative staff and persons providing supervision for PSS.

**9.1 Number of Staff Designated to Provide Parent Support**

On questionnaires, parent support specialists were asked about their employment status. Of 41 PSS who responded,

- 30 (73.2%) are full-time employees with benefits;
- 1 (2.4%) is a full-time employee without benefits;
- 6 (14.6%) serve in blended roles (e.g., wraparound facilitation and parent support services); and
- 4 (9.8%) indicated “other” including intake personnel, part-time PSS, PSS three quarter time, an interpreter, and a group leader.

Findings from focus groups support questionnaire findings regarding the proportions of staff designated to provide PSS services. Of the 22 PSS at the 8 agencies that participated in focus groups, 86% (19) of PSS were designated as full-time and received benefits; and 14% (3) were designated as part-time (data analyzed did not have benefits information for part-time PSS).

One agency had a bilingual (Spanish speaking) PSS, and another agency had a vacancy for a bilingual PSS.

**9.2 Caseload Sizes for Parent Support Specialists**

Caseload sizes for PSS are provided in Table 2.

- The caseload sizes of the 30 full-time PSS ranged from 8 to 80, with a mean size of 35.9 cases.
- The caseload sizes of the 6 PSS who serve in blended roles ranged from 3 to 75, with a mean size of 24 cases.
- The caseload sizes of PSS who described their positions as other (including part-time PSS, interpreter, and a group leader) ranged from 2 to 40, with a mean of 22.8.
- Overall, PSS caseload sizes ranged from 2 to 80, with a mean of 32.8.

In feedback, PSS gave potential reasons caseloads might be high. Some parents may only need low frequency contact and utilize PSS on an as needed basis. In other agencies PSS may count all the parents that attend weekly support groups of 15 to 20 participants.
Table 2. PSS Caseload Sizes

<table>
<thead>
<tr>
<th>Type of Position Held</th>
<th>Range</th>
<th>Mean Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-Time PSS (n = 30)</td>
<td>8 to 80</td>
<td>35.9</td>
</tr>
<tr>
<td>Blended Roles (n = 6)</td>
<td>3 to 75</td>
<td>24</td>
</tr>
<tr>
<td>Other (n = 4)</td>
<td>2 to 40</td>
<td>22.8</td>
</tr>
<tr>
<td>Totals (n = 40)</td>
<td>2 to 80</td>
<td>32.8</td>
</tr>
</tbody>
</table>

Focus group participants indicated that caseload sizes varied from agency to agency as well. Parent support specialists reported a caseload of 50-75 parents per worker in an urban agency and a caseload of 27-35 parents in more rural agencies. One agency was unsure of caseload size and said their PSS just “sees as many as she can see.”

9.2.1 Excess Demands and Limited Supply of PSS Resources

Three direct service staff groups and one group of parents said that there is more demand for PSS services than available supply. Parent support specialists and direct service staff expressed concerns due to high caseloads. PSS generally respond to families who have the highest needs. This crisis response mode is an intense level of interaction. In some situations, PSS have difficulty responding to families in a timely manner or making connections upon the initial referral if the family is not in crisis. In some places, PSS were unable to fulfill primary functions because case loads were too high.

If you look at it, 160 work hours in a month, and with a caseload of 75, it barely divides into 2 hours possibly a month for one client. And you throw in paperwork and other demands of having a job, it leaves very little time to see every kid and try to meet every need with such high caseloads.

Direct Service Staff

Yeah, I think the biggest thing is to help find a way to get those caseloads reduced. I mean 75, that’s just too much, way, way, way too much. And you’re breaking it down, that’s even if you’re seeing families all the time, which you’re not. So most of them have resorted to when there’s a crisis, when things break down, give me a call. Most of the time when there is a crisis they’re not going to call a parent support worker. Who are they going to call first? The case manager, of course. They’re going to call us and so they’re usually the last people on the list anyway. They’re behind the 8 ball to start off with, and when you’ve got such a high worker to client ratio, there’s just nothing you can really do. You have to be in a crisis mode and reactive kind of situation. I can understand why they wouldn’t have time to help families locate community resources because you don’t have time to do it because you’ve got one crisis and then you get another and then oh, you’ve got another family coming in. I would be like this isn’t worth it. I don’t know how much they get paid, but I would just be more inclined to quit, because we as case managers have a hard enough time with 15 kids.

Direct Service Staff
9.2.2 Need for More Parent Support Specialist Services

In general, all agencies expressed the need for an increase in PSS services. Specific special needs identified were PSS with sign language skills and PSS to serve the representative minority populations in their communities.

Administrators were asked what is necessary to hire more PSS. Agency representatives said they had to have a way to generate revenue and show an established need. Next steps were obtaining the position approved by the Executive Director and/or human resources and demonstrating need as well as where the funding to hire would come from in the budget. Three groups mentioned the need to reclassify the service under the general Medicaid state plan to support the growth of PSS services within their agencies.

9.3 View of Parent Support Specialists by Other Agency Service Providers

Parent support specialists were asked to respond to the statement, “Generally, I feel valued and respected by other CMHC service providers.” Of 42 PSS who responded to a scale from 1 to 5, with 1 indicative of never and 5 indicative of always, the mean score was 4.07. The PSS responses included the following:

- 35.7% (15) always;
- 38.1% (16) often feel valued and respected by other CMHC service providers;
- 23.8% (10) sometimes feel valued and respected by other CMHC service providers; and
- 2.4% (1) rarely feel valued and respected by other CMHC service providers.

9.3.1 Value and Respect for Parent Support

Overall, the majority of the direct service staff and administrative staff interviews identified multiple ways in which they valued and respected the work that PSS do on the treatment teams. More will be discussed regarding providers’ perspectives on how PSS enhance the CMHC treatment process in the section on how parent support functions engage families in the community mental health treatment process.

*We love our parent support…..Yes we do….We would really be lost without them on so many levels. Our administrators, they both value parent support very highly and it comes across.*

*Direct Service Staff*

*The culture of the agency, I think there’s a general consensus that this is a valued staff person and a valued part of the service array, particularly among CBS staff.*

*Administrator*

- **Support Communicating With Parents**

Providers indicated they valued the extra support communicating with parents.
Basically the consensus of our office is it would just be pure hell if we didn’t have her. We’re being serious. We’ve not had the parent support and then we got one in September and I can’t even imagine going back to what we had before. She alleviates so much stress of ours by dealing with the parents…. It’s vital to us PSS continue.

Direct Service Staff

- **Unique Perspective on Treatment Team**

Providers indicated they valued the unique perspective PSS bring to the treatment team.

She offers a perspective that I can’t, and that’s really great. I don’t have children, so some of my parents look at me and they don’t find my information very credible, so when I refer PSS to them she can give them a perspective that I couldn’t offer to the parents otherwise.

Direct Service Staff

- **Approach and Personal Attributes**

Providers indicated they valued the approach and personal attributes PSS bring to the helping process.

I think for me it’s really amazing in parent support, their ability to be professional to the point but also have empathy and be creative. They can say something that’s very direct but it’s not coming across as threatening.

Direct Service Staff

9.4 Membership on Wraparound Teams

Of the children who had wraparound teams and whose parents received parent support, on average, PSS reported being team members over 50% of the time.

Considering administrators and providers responses to how valuable PSS are to the treatment teams, 50% membership on wraparound teams is a surprisingly low finding. It is plausible questionnaire respondents were under the impression that membership on teams meant that they were in actual attendance at wraparound meetings. Parent support specialists may have been involved helping to facilitate the wraparound model of service delivery, which would indirectly make them a part of the wraparound team.

9.5 Access to Support in Agencies

Parent support specialists were asked to rate their agreement with the statement, “I have access to someone helpful for support.” Of 41 PSS who responded to a scale from 1 to 5, with 1 indicative of never and 5 indicative of always, the mean score on this item was 4.12. The PSS responses included the following:
- 46.3% (19) always have access to someone helpful for support;
- 29.3% (12) often have access to someone helpful for support;
- 17.1% (7) sometimes have access to someone helpful for support;
- 4.9% (2) rarely have access to someone helpful for support; and
- 2.4% (1) never have access to someone helpful for support.

**Summary Study Question 9: What Are the Dynamics Surrounding Staffing of Parent Support Specialist Positions?**

In summary, questionnaires and focus group findings support that the majority of PSS staff were full-time employees with benefits. Caseload sizes reportedly vary from center to center (range 2 to 80) with an average of 35. It was the consensus of respondents that more PSS were needed. However, agency representatives said they did not have a way to generate revenue to provide the service and thus could not find a source for funding more positions. Parent support specialists are highly valued by service providers in their agencies, and most feel supported by their respective agencies.
Study Question 10: What Billing Mechanisms Are Utilized for Parent Support Services?

In addition to data from the PSS questionnaires, this question was answered with qualitative data from interviews with administrative staff and persons providing PSS supervision.

10.1 Parents Served by Payment Source

On questionnaires, parent support specialists were asked to estimate the percentage of parents they serve according to payment sources. PSS estimated that

- 58.4% of their services were billed to the HCBS-SED Waiver;
- 32.8% to the Family-Centered System of Care grants;
- 2.4% of parents were on a private pay basis; and
- 6.3% of services were billed to other payment sources (not listed).

10.2 Billable Expectations

On questionnaires, PSS were asked to indicate if they work under an expectation that they have a certain number of billable hours. 39 PSS who responded,

- 94.9% (37) answered yes; and
- 5.1% (2) answered no.

10.2.1 Average Monthly Billable Expectations

On questionnaires, PSS were asked to provide an approximate number of monthly billable hours expected. Thirty PSS responded with an approximate number and two PSS responded with an approximate range. The range responses were excluded from the analysis in order to calculate an average billable expectation. Of 28 PSS, the average amount of billable hours expected of them per month was, 62.7 hours.

10.2.2 Monthly Hours Spent With Families and Billable Time

On questionnaires, PSS reported the frequency with which they tracked their billable time. Of 42 PSS who responded to a scale from 1 to 5, with 1 indicative of never and 5 indicative of always, the mean score on this item was 4.52. The PSS responses included the following:

- 69.0% (29) always track their billable time;
- 16.7% (7) often track their billable time;
- 11.9% (5) sometimes track their billable time; and
- 2.4% (1) rarely track their billable time.

In addition, on questionnaires, PSS were asked to estimate the average amount of time spent with families monthly and the average amount of time spent with families monthly that was billable. Of 34 PSS, the estimated average amount of time spent with families...
monthly was 66.3 hours, and the estimated average amount of time spent with families monthly that was billable was 40.2 hours.

Focus group findings from three agencies suggest that a majority of the work PSS do is not billable. Percentages reported ranged from 75 to 95%. An additional five agencies were unsure about non-billable hour estimates.

In addition, focus group findings indicated that PSS could only bill for individualized PSS services they provided to parents if youth were receiving the HCBS-SED waiver.

10.3 Tracking Family-Centered System of Care (FCSC) Funding

The Family-Centered System of Care (FCSC) grants were intended to be used to cover the cost of the PSS services for families who were not receiving the HCBS-SED waiver.

On questionnaires, PSS were asked about the frequency with which they track the amount of time billed to the FCSC grants. Of the 35 PSS who responded to a scale from 1 to 5, with 1 indicative of never and 5 indicative of always, the mean score on this item was 2.74. The PSS responses included the following:

- 34.3% (12) always track time billed to FCSC grants;
- 8.6% (3) often track time billed to FCSC grants;
- 5.7% (2) sometimes track time billed to FCSC grants; and
- 51.4% (18) never track time billed to FCSC grants.

Administrative staff, supervisors and PSS were asked how they track PSS services provided by the FCSC grant in interviews.

Parent support specialist positions were funded by FCSC; without this funding, the positions would be closed. The majority of the agencies (7) were providing PSS services to all families, regardless of payment source. However, families who were on the HCBS-SED Waiver were prioritized.

Most agencies in the study had no specific tracking mechanism for the expenditure of FCSC funds; rather they recorded hours of face to face services or had an agency code that PSS reported to billing departments on a regular basis. However, one agency tracked all services provided by PSS by the hour and could account for every dollar spent on the FCSC grant. This agency also tracked multiple other sources of grant funding for their PSS program.
Summary Study Question 10: What Billing Mechanisms Are Utilized for Parent Support Services?

Questionnaire and focus group findings indicated that the majority of work PSS do is not billable, yet most PSS have billable requirements they must meet. Parent support specialists estimated that the majority of the services they provide were billed to the HCBS-SED Waiver and the FCSC grants, 58% and 33% respectively. On contact hour requirements, consensus from focus groups findings was that families receiving the waiver were prioritized but that most agencies serve all families, regardless of their third party coverage status. Family-Centered System of Care (FCSC) billable services and outputs (ie. PSS services provided) are loosely tracked in the current system. The majority of PSS indicated that they rarely track the amount of time billed specifically to the FCSC grant funds. The exception was one agency that could track every dollar spent on their FCSC grant.
VALUE OF PARENT SUPPORT SPECIALIST SERVICES

Study Question 11: What Is the Value of Parent Support Services?

- 11.1: Are Parent Support Services Related to the Goals on Youth’s Plans of Care?
- 11.2: Are the Parent Support Services Provided to Parents Helpful to Their Children?
- 11.3: Are Some PSS Functions More Helpful Than Others?
- 11.4: Are Parent Support Services Associated With Improvement in the Conditions for Which Children Are Receiving Community Based Services?

11.1: Are Parent Support Services Related to the Goals on Youth’s Plans of Care?

In addition to data from parent questionnaires and PSS questionnaires, this question was answered with qualitative data from focus groups with parents, direct service providers, and parents and interviews with persons providing supervision for PSS.

11.1.1 Parent Perception of Goal Attainment

On questionnaires, parents were asked about the relationship between parent support services and achieving goals on their children’s plans of care. Of 146 parents who responded to a scale from 1 to 4, with 1 indicative of strong disagreement and 4 indicative of strong agreement, the mean score on this item was 3.60. The parent responses included the following:

- 62.3% (91) strongly agreed that PSS services help achieve goals on their children’s plans of care;
- 35.6% (52) agreed that PSS services help achieve goals on their children’s plans of care; and
- 2.1% (3) disagreed that PSS services help achieve goals on their children’s plans of care;

11.1.2 Parent Support Specialists’ Perception of Goal Attainment

On questionnaires, PSS were asked to assess how often the services they provide parents assist parents in helping their child accomplish the goals and objectives on their plans of care. Of 42 PSS who responded to a scale from 1 to 5, with 1 indicative of never and 5 indicative of always, the mean score on this item was 4.02. The PSS responses included the following:

- 16.7% (7) PSS services always help achieve goals on children’s plans of care;
- 69% (29) PSS services often help achieve goals on children’s plans of care; and
- 14.3% (6) PSS services sometimes help achieve goals on children’s plans of care.
11.1.3 Role of Parent Support in Goal Attainment

The majority of interview data suggest that parent support services are related to the goals on the plan of care and are helpful to accomplish and achieve these goals.

- **Facilitation of Family Engagement in Goal Attainment**

  The bridging functions (discussed on page 34) that PSS provide are particularly helpful in establishing goals that are meaningful to the families and the overall treatment planning process. For instance, parents and direct service staff have said that PSS are helpful because they break the goals down into smaller more achievable steps, ensure that family concerns are addressed in goal development as well as provide parents with a better understanding of the terminology. All of these tasks help facilitate family engagement in goal development and overall mental health center treatment planning.

  As far as establishing goals with my kids, when I know that we’re getting ready to come up on that, what is it, every 3 months that you redo them? I kind of know when my kids are coming up, so I usually call PSS and say I have no idea if we’ve met what, I have no clue, and we will talk about each individual kid and usually my PSS does all the writing, because I’ll just like well, what do you think about this with this one? So we go through a list so that when my kids’ case manager comes I can say well, what do you think about this? Because otherwise I don’t have the proper language to put on the paper for it to be accepted as a case treatment plan. She gives me the words to get it on the paper so that it’s going to get whatever needs to be met. She helps me talk about it.

  **Parent**

- **Facilitation of Team Awareness of Goals of Services**

  In two agencies, direct service staff were especially grateful to have PSS because they help keep the focus on the goals and provide a constant check on their relevancy to current treatment.

  She’s very good about remembering okay, if everybody’s starting to feel a little lost, let’s go back to the goal. What was the original goal? Do we need to change it? Do we need to add to it? Do we need to take it out? I’ve heard her say, and I’ve learned this and I say this too. **This document is a living document. It’s not something we just etch out in stone and then it’s gone and we can’t change it or revise it or add to it.** She’s good about remembering to bring that out and say look. This was my role, this is what I said I was going to do. I said I was going to teach parenting skills.

  **Direct Service Staff**
I think parent support really keeps the goals up front with the parent, keeps reminding them of the goals. There’s the follow-up through parent support. Where a lot of us maybe have forgotten, she’s really kind of the flag bearer to keep us all aware of the goals of the services that are provided.

Direct Service Staff

I had a situation very recently where you visit with the parents and they tell you the things that they have concerns with, and a lot of times it’s the same old things. She had expressed the concern about her son’s academic performance to the parent support worker and the parent support worker then came to me and mentioned it. And I knew that when she went to the parent support worker with it that this just wasn’t the same old thing. This was something that she was really, really concerned with. So I got back in touch with her, got in touch with the consumer, and put more emphasis on academics. Because I had heard it so many times over the past year or so that I really didn’t give it the attention that it needed. The parent support worker became like a liaison, it’s not that I wasn’t listening to the parent, but when she went and mentioned the same thing to her, I thought wow, this really is a big concern of hers, bigger than usual. I went back to the parent and we worked things out and we gave it the attention that it needed.

Direct Service Staff

Summary Study Question 11.1: Are Parent Support Services Related to the Goals on Youth’s Plans of Care?

All data sources indicate PSS services help parents help their children accomplish goals on their children’s plans of care. The bridging function (discussed on page 34) is particularly useful to help parents engage in goal attainment. Focus group data indicated that PSS enhance goal attainment by breaking goals down into smaller achievable steps, assuring family concerns are represented in goal development, and providing parents with a better understanding of mental health terminology. Direct service staff in two agencies found PSS particularly useful because they serve as a reminder to all providers on the treatment team as well as parents in regard to the goals or purposes for the services provided to families.
11.2: Are the Parent Support Services Provided to Parents Helpful to Their Children?

11.2.1 Parent Perception of Child Behavior Management

On questionnaires, parents were asked to indicate their level of agreement with the statement, “The parent support services I receive help me manage my child’s behavior or symptoms.” Of 147 parents who responded to a scale from 1 to 4, with 1 indicative of strong disagreement and 4 of strong agreement, the mean score for this item was 3.58. The parent responses included the following:

- 61.9% (91) strongly agreed that parent support services help manage children’s behavior or symptoms;
- 34% (50) agreed that parent support services help manage children’s behavior or symptoms; and
- 4.1% (6) disagreed that parent support services help manage children’s behavior or symptoms.

11.2.2 Parent Perception of Family Functioning and Child-Well Being

On questionnaires, parents were asked to indicate their level of agreement with the statement, “When my PSS helps with things such as school issues, dealing with my child’s behavior, and finding community resources, it improves our family functioning and my child's well-being.” Of 144 parents who responded to a scale from 1 to 4, with 1 indicative of strong disagreement and 4 of strong agreement, the mean score for this item was 3.68. The parent responses included the following:

- 70.1% (101) strongly agreed that PSS improve family functioning and children’s well-being;
- 27.8% (40) agreed that PSS improve family functioning and children’s well-being; and
- 2.1% (3) disagreed that PSS improve family functioning and children’s well-being.

11.2.3 Parent Perception of Helpfulness of PSS Services

On questionnaires, parents were asked to indicate how helpful PSS services were in “assisting you to help your child improve their behavior problems or symptoms.” Of 131 parents who responded to a scale from 1 to 4 with 1 indicative of not helpful and 4 extremely helpful, the mean score for this item was 3.78. The parent responses included the following:

- 80.2% (105) of parents indicated that PSS services are extremely helpful;
- 17.6% (23) of parents indicated that PSS services are very helpful; and
- 2.3% (3) of parents indicated that PSS services are slightly helpful.
11.2.4 Parent Perception of Helpfulness of All Community Based Services

In addition, on the questionnaires, parents were asked to indicate how helpful various other CBS were in assisting them to help their children improve their behavioral problems or symptoms. Many parents said it was difficult to rate the helpfulness of specific services because it was the array of services and the team approach to service provision that they found most helpful. From a sample of 149 parents, 131 provided ratings of the helpfulness of the various CBS services. Averages of all service ratings ranged from 3.19 to 3.78, indicating that parents find all the CBS services they receive to be very helpful.

11.2.5 Impact of Interventions on Children’s Environments and Parenting Abilities

Volumes of interview data support the quantitative findings that parent support services provided to parents are helpful to their children. Parent support specialists impact a critical aspect of child’s ecosystem, the parent. Providing the needed support to the parents promotes the success of the child.

- Parents Gain Confidence

The primary functions PSS provide to parents lead to increased parenting abilities. Parents gain confidence in their parenting abilities which improves children’s home environments.

She’s the one that’s learned to give me the information. And without her, I would not be where I am at now. And I’ve had 5 years of parent support. I’m very different than I was 5 years ago. I handle situations different. I deal with my children differently. I handle them better. I joke a lot like I was talking about the bottomless pit. Five years ago it wouldn’t have been funny. That’s what it would have felt like. It wouldn’t have been a joke. But I can joke about it now, make it sound funny, but yet still bring the reality into it. Because everybody understands that it’s a joke, but they also understand that’s our reality. That’s what you feel like, like you’re in this black, bottomless pit. And so without her, no, I would not be where I am at. My children would not be where they’re at. They are much better off because of her, even though she doesn’t work directly with them. They feel the effects of everything she teaches me.

Parent

- Parents Gain Stress Management Skills

Specifically, by teaching parents self-care strategies, parents are less reactive to stress they experience as a result of managing their children’s behaviors. Overall the home environment is calmer and more peaceful for the children.

It makes you stay a better and happier person so you can present that to the kids. If we were stressed all the time and tensed all the time on every little thing that the child does, then it wouldn’t be good. It would create a negative environment. But yeah, your parent support can help give you the tools and the calmness of...
how to stay more stress-free, calmer and think things through, so you can have a calmer environment.

Parent

If you help their parents, you're helping the kids, at least that's how I see it. She models for parents so well, but then you hope there's a good trickle-down to the family and to the interaction with the children. I think she helps parents understand their child’s illness and it's less personal and it's more about looking at their strengths. The child is more than just ADHD or more than just asperger’s. And helping the parents take care of themselves means they can be a better parent. They can be more available to their children. So I see her do that very well and certainly then the kids benefit from that so much.

Direct Service Staff

▪ Parents Learn New Parenting Techniques

By attending parenting classes or getting information regarding parenting techniques from PSS, parents learn new skills or tools from PSS to help manage their children’s behaviors in stressful situations.

Parent Support teaches the Love and Logic program to a lot of families and I've been involved with her with one family in particular that we were resuming services and I was a new therapist coming in and she went with me to the home. The family remembered Love and Logic. They were no longer using it. They had let it go by the wayside. But they remembered it. So it had been taught and it had been observed. They in their normal family structure had let it slide, but it wasn't hard for them to pick up the pieces again and use that same vocabulary to get them back to a better structure. So the Love and Logic seems to be a really helpful piece to some families in particular that I've seen.

Therapist

▪ Parents Model Stress Management Techniques

By learning these new techniques from PSS, parents become a model for their children of how to manage stressful situations and frustration.

My child sees that I do get angry and upset. He's seen that some of the ways of coping for him is also the way I cope. So he picks up some of my coping. There have been times when he'll look at me and he goes I'm going to my room. Just because he knows we need to separate. My parent support says parents need time out too. She says parents throw tantrums, too.

Parent
Parents Gain Peer Support and Hope

Parent support specialists facilitate peer support (see page 37), which decreases the isolation parents feel. These connections establish a support network where parents gain hope to hang in there with their children through the difficult times.

Parent Comments:

*It’s a place to cry. It’s a place to hear other stories. And it’s sad to say, but it’s a place that even though you’re coming depressed, usually everybody’s depressed, we all leave laughing, smiles on our face.*

*We laugh at inappropriate things together.*

*We’re very inappropriate.*

*We call it laughing in the face of tragedy.*

*And even 5 or 10 minutes, if you can forget your own and empathize with somebody else, that helps.*

*The acceptance in the group is the most wonderful thing in the world. After being in all these meetings where people are doing this, to have everybody going oh yeah. It’s so wonderful because so many times parents haven’t had any group.*

Parents Gain Knowledge and Aptitude to Access Community Resources

Parent support specialists link parents with resources in the community. Sometimes the purpose of linking is to help meet the families’ basic needs for utilities, food, or shelter. Other times PSS are teaching parents how to obtain the community resources by walking them through the steps to access what is needed. Through these linking interventions, parents learn skills, become more self-sufficient, and are able to meet their children’s needs.

*If you’re working with the parent and you’re calming them down and you’re giving them tools and you’re giving them resources. Say they don’t have money to pay their rent then you teach them how to make some calls and get some help, or you help them get a job, or you help them go apply for SSI. By doing these things you address the frustrations come back with the budget. That’s going to be that much more patience that they have to deal with their child when they’re acting up. Everything that we do to support and help a parent has to benefit that child.*

Parent Support
11.2.6 Role of PSS in Helping Parents Find Constructive Ways to Be Involved in Their Children’s Lives

I don’t think involvement is the right word. We’re going to be involved in our children’s life. I think that the way we’re involved in our children’s life is better because of parent support. How I deal with problems right now is not how I would have reacted 5 years ago. I would have lost my temper more, I would have screamed more, I wouldn’t have handled it more, I would have broke down more…

Parent

- Parents Understand the Treatment Process

The functions PSS perform help parents understand how to be active in the community mental health treatment process leading to better results in treatment for their children. For instance, by translating and facilitating parents’ understanding of the importance of parent involvement in goal development and attainment, parents learn what they can do to help achieve the goal in the home.

I think being able to help the parent become engaged in the treatment process and come to a point where they have really invested interest, because it doesn’t always start out that way. It’s more of fix my child. And having the parent actually have a person that is really there for them and helping them understand the process is very different than what they’re usually accustomed to. They come to a point where they really invest a lot more time and energy into the life of their child or children, because families have multiple kids in services. They come to a point where they really understand the importance of that and that without their time, interest, things just are not going to progress as quickly as they would like to see. For me, that seems to be the number one importance of having a parent support worker with the family.

Supervisor

I think by supporting the parents it does help the kid achieve their goal, because sometimes the parents don’t know where to get involved in the kid’s goal. They leave it up to the case manager or the therapist to complete that goal. The parent support does a good job at supporting the parent to get involved in the goal. How can you help it? What’s going to make the difference in the home?

Direct Service Staff

- Parents Understand Children’s Mental Illness and See Potential

Furthermore, by providing information and helping parents understand their children’s challenges, parent support specialists help parents see beyond the illness and focus on their children’s potential.

She’s even in plan of cares had to help a parent remember that there are many strengths about your child, even if it’s going to take me to tell you. And she
doesn’t judge them by doing that. She’s good about that, helping a parent see through her eyes, maybe, on how she sees their child, instead of focusing on the negative behavior that they live with every day. The temper tantrums, the disrespect, the kicking holes in my wall and peeing on my floor. It’s kind of hard to remember your child has good traits about them when they’re doing that. But parent support is, by educating them I think, and getting to know the child, obviously, from being in the home. She’s good about bringing that to a goal, making it into a goal and reminding everybody, even if it is on a plan of care, there’s many, many strengths that this family has. That’s the other thing. She pulls the family strengths together. She doesn’t just focus on one thing. She’s good about pulling what are the strengths this family has. What makes this unit work? That turns into goals easily.

Direct Service Staff

With parents focused on their children’s potential, children more readily participate in treatment because they have a better relationship with their parents and want to do well. The children are more relaxed in treatment because their parents are relaxed.

11.2.7 Increase in Efficiency of CMHC Services to the Entire Family

The primary functions PSS perform increase the efficiency of CMHC services to the entire family.

- Emotional Support Prevents the Need for More Services

For instance, by providing the additional emotional support to parents in stressful situations, parent support diverts the need for more mental health providers to be assigned.

I’m thinking of a particular family. I think parent supports goes in and listens and supports and decreases some stress in the family, and that does a couple of things. It prevents the need for other mental health services having to be utilized, because that takes care of that, and hopefully it starts to shape some healthiness in that family, in that home or that classroom or wherever it is. That just makes it an easier or a little healthier place for that kid to be.

Therapist

- Crisis Interventions Divert Out of Home Placements

In addition, by providing crisis coaching, being accessible, and listening to parents, PSS are diverting potential out of home placements (e.g., psychiatric hospitalization, child welfare involvement).

When we’re sitting there in our living room in tears over whatever crisis or thing that’s going on, she cares. And she doesn’t make fun of us for having the tears or getting angry because we can’t resolve this in an adult way, for lack of a better word. She’s just there.
Parent

I’ve made the phone calls at 4:00 in the morning. I’ve sent the text messages when I’m sitting on my dryer crying, at my wit’s end, because I can’t get anybody else on the line. She didn’t fix anything, but she listened. She listened when I was at my wit’s end and she got reamed pretty good for that. But there wouldn’t have been a 3 year old alive and I probably wouldn’t have been alive that night had she not picked up that phone. And what they don’t understand, you overstepped your boundaries. The hell with boundaries at that point. **It was a 3 year old’s life that was saved. That was my life that was saved, because I didn’t want a 3 year old at that time.**

Parent

- **Parenting Techniques Provided by PSS Help Prevent Out of Home Placements**

By providing hands-on parenting techniques and teaching skills, PSS help parents restructure the home environment to keep their children in their homes.

We have a teenage boy who we’ve been trying to keep out of level 6 placement. It seems like the progress that has been made has not been necessarily with him but a change in his home environment. The parent support worker played a key role in that in helping restructure the environment as well as providing the parent the support that she needed. **The parent also had mental illness and so the parent support worker was very sensitive to that and able to work with her to help her re-structure the environment and help her know how to parent this kid.** And therefore we have diverted him from level 6 successfully and know things are going great.

Direct Service Staff

- **Assistance With School Process Helps Maintain Youth in Home Schools**

Lastly, by providing information regarding the IEP process and assisting parents navigating in the school systems, parent support specialists help keep children with SED in their home schools.

Just teaching you to be an advocate for your child is a major importance. You can’t just let things happen. You’ve got to fight for what your child needs. She shows you how to do that without stepping on too many toes, like during the IEP meetings, going there with knowledge, because not by just power, but watch how you say it. Don’t be defensive. She’s like your cheerleader. She doesn’t say it in a lecturing way. That helps a lot.

Parent

**11.2.8 Benefits of Parent Support Services on Parents Observed by Children**

He wanted to know if he should come tonight. He doesn’t engage, normally. That was amazing. He has more of a calmness, maturity, patience.
Parent

My child tells me to call parent support, you know, that friend that helps you?

Parent

Summary Study Question 11.2: Are the Parent Support Services Provided to Parents Helpful to Their Children?

The large majority of parents agreed that the PSS services they received helped them manage their children’s behavior or symptoms. Furthermore the large majority of parents agreed that PSS helps improve family functioning and child well-being. Qualitative findings indicate that PSS interventions impact the children’s environments by increasing parenting resilience, supporting parents to be involved in their children’s lives, and increasing the efficiency of the CMCH services to the entire family.

With regard to improving parenting resilience, findings indicate that parents increase confidence, stress management skills, parenting techniques, peer support, and knowledge of community resources. In addition, parents become a model for their children on how to manage stress.

Parent support specialists encourage parents to be involved by helping them understand how to be active in the treatment process. For instance, PSS facilitate parent involvement in goal attainment and help them understand their children’s illness as well as potential. With parents focused on their children’s potential and engaged in goal attainment, children are more relaxed and treatment progresses at a faster rate.

The main purpose of community based service is to maintain children with an SED in the least restrictive placement that will meet their needs. Functions PSS perform increase the efficiency of CBS services to achieve this purpose. Parent support specialists do this by providing emotional support to parents which prevents the need for other services to be accessed. In addition, this support can be very effective in crisis situations to help parents manage the stress or learn techniques to manage the crisis. Furthermore, PSS help support parents in navigating the school system on behalf of their children. Without this crucial support, some children would be placed in more restrictive school placements.

The parents reported that children even notice the impact that PSS services have on their parents.
Study Question 11.3: Are Some PSS Functions More Helpful Than Others?

Findings from parent questionnaires are presented in the list below, which holds the specific components of parent support programs as well as mean parental ratings of their helpfulness based on a scale from 1 to 4, with 1 indicative of not helpful and 4 indicative of extremely helpful. Parents clearly found all the functions PSS perform as helpful with a mean range from 3.349 to 3.8. Ratings were all high and the integers of the mean scores were extended in order to note differences.

Parents found emotional support most helpful (3.8), followed by assistance during crisis (3.68), support and encouragement to have voice in their child’s service planning (3.672), holding family support groups (3.669), and telling them about things at the mental health center such as available services and service providers (3.648).

Parental Ratings of Parent Support Program Components:

1. Provides support for whatever reason needed such as listening and letting me know I am not alone - 3.80 (145).
2. Helps our family when our child is having a crisis - 3.68 (125).
3. Supports and encourages me to have voice in my child’s case plan at the mental health center - 3.672 (131).
4. Holds family nights/parent support groups for parents - 3.669 (121).
5. Tells me about things at the mental health center, such as services that are available and service providers - 3.648 (142).
6. Talks with other service providers at the mental health center for the betterment of my child/family - 3.64 (136).
7. Talks to others on my behalf such as staff from school or other agencies - 3.639 (122).
8. Attends IEP meetings or other school meetings with me - 3.621 (103).
9. Helps me better understand what other service providers tell me, such as therapists - 3.591 (127).
10. Supports me at meetings or events other than at school, such as going to court - 3.590 (95).
11. Helps me learn ways to prevent crises with my child - 3.565 (131).
13. Helps me complete paperwork like CBCLs or for the waiver or government agencies - 3.551 (109).
14. Educates and informs me about federal and state regulations around school issues, including IEPs - 3.543 (127).
15. Provides workshops on subjects such as childhood development and information about my child’s diagnosis - 3.529 (121).

16. Advocates and informs me about child/parent rights within my child’s school district - 3.519 (129).

17. Helps me cope with stress and manage my household, including things like setting priorities, paying bills, and taking care of myself - 3.519 (133).

18. Tells me what I can expect from other organizations such as SRS and the courts - 3.519 (108).

19. Helps me use what I learn in workshops or parenting classes with my child in the home - 3.5 (116).

20. Assists our family with resources in the community - 3.496 (125).


22. Serves as negotiator between me and CMHC staff to resolve issues or differences that arise - 3.474 (97).

23. Provides transportation for me and/or my child to appointments or activities at the mental health center - 3.474 (76).

24. Helps me use techniques with my child at home such as role playing or something the therapist suggested we try - 3.349 (126).

Summary Study Question 11.3: Are Some PSS Functions More Helpful Than Others?

Although parents found all components of PSS programs helpful, questionnaire data indicate that parents found emotional support, followed by support and encouragement to have voice in their child’s service planning, holding family support groups, assistance during crises, and talking with other services providers on behalf of the parent as the top five most helpful components of PSS programs.
Study Question 11.4: Are Parent Support Services Associated With Improvement in the Conditions for Which Children Are Receiving Community Based Services?

In addition to parent questionnaires, this question was answered with qualitative data from focus groups with parents and direct service staff and interviews with administrative staff and persons providing supervision for PSS.

11.4.1 Parental Rating of Child Improvement

On questionnaires, parents were asked to indicate their level of agreement with the statement, “The parent support services I receive help me help improve the condition for which my child is receiving services at the mental health center.” Of 146 parents who responded to a scale from 1 to 4, with 1 representing strong disagreement and 4 representing strong agreement, the mean parental rating on this item was 3.64. The parent responses included the following,

- 98 (67.1%) expressed strong agreement with the statement;
- 44 (30.1%) agreed with the statement;
- 3 (2.1%) disagreed with the statement; and
- 1 (0.7%) strongly disagreed with the statement.

11.4.2 PSS Rating of Child Improvement

On questionnaires, parent support specialists were asked to respond to the statement, “The services I provide parents help them help their child improve the conditions for which they are receiving services at the CMHC.” Of 40 PSS who responded,

- 6 (15%) reported this is always the case;
- 32 (80%) reported this is often the case; and
- 2 (5%) reported this is sometimes the case.

Qualitative findings from both parent support specialist questionnaires and interview data are identical to the findings in section 11.2.3-11.2.6, beginning on page 72. When stakeholders were discussing how parent support services were helpful to help their children, they were also discussing how services were helpful to improve the condition for which children were receiving services.
Summary Study Question 11.4: Are Parent Support Services Associated with Improvement in the Conditions for Which Children are Receiving Community Based Services?

The majority of parents (97%) agreed that PSS services helped improve the conditions for which their children were receiving services at the mental center. The majority of PSS (95%) indicated that the services they provided to parents helped parents improve the conditions for which they were receiving services at the CMHC. Focus group findings supported questionnaire findings and explained how PSS services were associated with the improvement in the children. PSS services improved parenting outcomes for children who experience SED which in turn improved conditions for which children were receiving services at the CMHC.
CLIENT STATUS REPORT OUTCOMES

Study Question 12: Do the Client Status Report Outcomes of Children Whose Parents Receive Parent Support Services Differ From Those Whose Parents Do Not Receive These Services?

This question was answered with quantitative data contained in a database utilized for another study completed by KU (Barfield et al., 2006). In that study, a database constructed from 377 random record reviews at CMHCs in Kansas was merged with Client Status Report (CSR) data.

As part of the SRS/HCP process of monitoring standards and quality assurance, all CMHCs in the State of Kansas are required to submit Client Status Reports (CSRs) on a quarterly basis. The CSRs contain extensive fields for tracking that include data such as demographics, services provided, custody status, reimbursement sources, and educational placement. The CSRs also contain outcome variables such as Residential Placement, Law Enforcement Contact, Academic Performance, School Attendance, and Child Behavior Checklist (CBCL) Scores. Quarterly reports issued based on the CSR submissions are used for a variety of purposes, including quality improvement.

For each year of this 3-year study, a sampling frame was generated for systematic random sampling of CSR data housed in the Automated Information Management System (AIMS). The AIMS database is described below.

The Automated Information Management System (AIMS) is a comprehensive data set that includes data on demographic, client status, and encounter data for individuals served through the Kansas Community Mental Health Centers. Data are used for a variety of purposes including federal and state quality improvement programs and to monitor CMHC contacts under Mental Health Reform. (Kansas Department of Social and Rehabilitation Services, p. 2)

The CSR outcome variables of Residential Status, Law Enforcement Contact, Academic Performance, and School Attendance, as well as change in CBCL scores, were examined for children whose parents received support and those who did not receive support. These findings are delineated in Tables 3, 4, 5, 6, and 7. Children whose parents received support had better outcomes on all variables than children whose parents did not. The residential status for children of parents receiving support was considerably better than those who were not. Youth whose parents received support had notably less law enforcement contact than those who did not. The academic performance of children whose parents received support was significantly better than those who did not. The school attendance of children whose parents received support was markedly better than those who did not.

The mean amount of improvement on both Internalizing and Externalizing CBCL scores from baseline, near the time of intake, to the last quarter of observation for each year of the study was significant for both the parent support group and the group without support. The mean amount of improvement in the Internalizing scores of children whose parents
received support and of children whose parents did not was the same. The mean amount of improvement in the Externalizing scores of children whose parents received support was considerably more than the improvement in the Externalizing scores of children whose parents did not, but the difference between the two groups was not statistically significant.

12.1 Residential Status

Per Table 3, of the 328 children matched on the variable of residential placement, 87 families (26.5%) received parent support services and 241 (73.5%) did not.

The residential status (children living in a stable home) for children of parents receiving support was considerably better than those whose parents were not.

<table>
<thead>
<tr>
<th>Residential Status</th>
<th>Received Parent Support</th>
<th>Did Not Receive Parent Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents (n = 290)</td>
<td>81 (93.1)</td>
<td>209 (86.7)</td>
</tr>
<tr>
<td>Relatives (n = 11)</td>
<td>1 (1.1)</td>
<td>10 (4.1)</td>
</tr>
<tr>
<td>Foster Homes (n = 17)</td>
<td>3 (3.4)</td>
<td>14 (5.8)</td>
</tr>
<tr>
<td>Independent Living (n = 1)</td>
<td>1 (1.1)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Residential Care (n = 5)</td>
<td>0 (0)</td>
<td>5 (2.1)</td>
</tr>
<tr>
<td>Legal Custody (n = 2)</td>
<td>1 (1.1)</td>
<td>1 (0.4)</td>
</tr>
<tr>
<td>Drug/Alcohol Treatment (n = 1)</td>
<td>0</td>
<td>1 (0.4)</td>
</tr>
<tr>
<td>Emergency Shelter (n = 1)</td>
<td>0</td>
<td>1 (0.4)</td>
</tr>
<tr>
<td>Totals (n = 328)</td>
<td>87 (100)</td>
<td>241 (100)</td>
</tr>
</tbody>
</table>

12.2 Law Enforcement Contact

Youth whose parents received support had markedly less law enforcement contact than youth whose parents did not receive support (Table 4).

<table>
<thead>
<tr>
<th>Contacts</th>
<th>Received Parent Support</th>
<th>Did Not Receive Parent Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>No contact (n = 302)</td>
<td>85 (96.6)</td>
<td>217 (88.9)</td>
</tr>
<tr>
<td>One contact (n = 17)</td>
<td>1 (1.1)</td>
<td>16 (6.6)</td>
</tr>
<tr>
<td>Two contacts (n = 10)</td>
<td>2 (2.3)</td>
<td>8 (3.3)</td>
</tr>
<tr>
<td>Three contacts (n = 2)</td>
<td>0 (0)</td>
<td>2 (0.8)</td>
</tr>
<tr>
<td>Four contacts (n = 1)</td>
<td>0 (0)</td>
<td>1 (0.4)</td>
</tr>
<tr>
<td>Total (n = 332)</td>
<td>88 (100)</td>
<td>244 (100)</td>
</tr>
</tbody>
</table>

*Difference in means .11 or 11% of one contact
12.3 Academic Performance

Children whose families received parent support demonstrated significantly better academic performance than children who did not (Table 5).

**Table 5. Academic Performance (n/%)**

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Received Parent Support n/%</th>
<th>Did Not Receive Parent Support n/%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average or above average (n = 266)</td>
<td>79 (91.9)</td>
<td>187 (83.1)</td>
</tr>
<tr>
<td>Failing or below average (n = 45)</td>
<td>7 (8.1)</td>
<td>38 (16.9)</td>
</tr>
<tr>
<td>Totals (n = 311)</td>
<td>86 (100)</td>
<td>225 (100)</td>
</tr>
<tr>
<td>Means*</td>
<td>3.33</td>
<td>3.06</td>
</tr>
</tbody>
</table>

*Based on scale from 1 to 4, with 1 indicative of failing grades, 2 of below average, 3 of average, and 4 of above average (A or B)
*Difference between means statistically significant (p < .02)

12.4 School Attendance

The school attendance of children whose parents received support was markedly better than those whose parents did not (Table 6).

**Table 6. School Attendance (n/%)**

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Received Parent Support n/%</th>
<th>Did Not Receive Parent Support n/%</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Attends regularly (n = 259)</td>
<td>76 (88.4)</td>
<td>183 (80.6)</td>
</tr>
<tr>
<td>3. Attends more than not (n = 35)</td>
<td>8 (9.3)</td>
<td>27 (11.9)</td>
</tr>
<tr>
<td>2. Attends infrequently (n = 11)</td>
<td>0 (0)</td>
<td>11 (4.8)</td>
</tr>
<tr>
<td>1. Not attending (n = 8)</td>
<td>2 (2.3)</td>
<td>6 (2.6)</td>
</tr>
<tr>
<td>Totals (n = 313)</td>
<td>86 (100)</td>
<td>227 (100)</td>
</tr>
<tr>
<td>Mean Score*</td>
<td>3.84</td>
<td>3.70</td>
</tr>
</tbody>
</table>

*Based on scale from 1 to 4, with 1 indicative of not attending and 4 of regular attendance
*Differences between means not significant
12.5 Child Behavior Check List (CBCL) Scores

Analyses were performed to determine differences in Internalizing and Externalizing CBCL scores from baseline, near the time of intake, to the last quarter of observation for each year of the study. Internalizing scores reflect somatic complaints, withdrawal, anxiety, or depression; and Externalizing scores reflect delinquent or aggressive behavior. The mean baseline, the mean last quarter, and the mean amount of change, on average, are given in Table 7.

Table 7. Internalizing and Externalizing CBCL Scores Change

<table>
<thead>
<tr>
<th>Score</th>
<th>Received Parent Support</th>
<th>Did Not Receive Parent Support</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Base-line</td>
</tr>
<tr>
<td>Mean of Internalizing score (n=323)</td>
<td>87</td>
<td>66.7</td>
</tr>
<tr>
<td>Mean of Externalizing score (n=323)</td>
<td>87</td>
<td>71.3</td>
</tr>
</tbody>
</table>

*Statistically significant improvement per paired t-tests (p < .02)
Summary Study Question 12: Do the Client Status Report Outcomes of Children Whose Parents Receive Parent Support Services Differ From Those Whose Parents Do Not Receive These Services?

In summary, children whose parents received support had better outcomes on all variables than children whose parents did not. The residential status for children of parents receiving support was considerably better than those who were not. Youth whose parents received support had notably less law enforcement contact than those who did not. The academic performance of children whose parents received support was significantly better than those who did not. The school attendance of children whose parents received support was markedly better than those who did not.

The mean amount of improvement on both Internalizing and Externalizing CBCL scores from baseline, near the time of intake, to the last quarter of observation for each year of the study was significant for both the parent support group and the group without support. The mean amount of improvement in the Internalizing scores of children whose parents received support and of children whose parents did not was the same. The mean amount of improvement in the Externalizing scores of children whose parents received support was considerably more than the improvement in the Externalizing scores of children whose parents did not, but the difference between the two groups was not statistically significant.
SUMMARY AND DISCUSSION

1. Support of Family Driven System of Care

Almost all PSS have experiences as caregivers or family members of children with SED (serious emotional disturbance) as well as experiences navigating multiple child serving systems. PSS approach their work from an environmental systems perspective, which purports that parents are the primary source of their children’s well-being and thus are a critical component of their children’s environments (Comer & Fraser, 1998). As such, PSS seek to improve parenting outcomes for children who experience SED. The President’s New Freedom Commission on Mental Health 2003 report (Department of Health and Human Services) indicates that mental health care is to be consumer and family driven. The PSS approach is family driven; recognizing parents’ expertise and encouraging full partnership in treatment planning by engaging parents all aspects of treatment planning from goal attainment to advocating on their child’s behalf.

2. Efficacy of Parent Support Specialist Services

2.1 Literature Review

There is strong support in the literature for the environmental approach PSS take to improving parenting outcomes for children who experience an SED. The children’s services systems literature indicates that parent support interventions impact family outcomes by improving parents’ ability to cope with rearing children with emotional difficulties, family relations, and children’s behavior (Davis & Rushton, 1991; Davis & Spurr, 1998; Koroloff & Friesen, 1991;) In addition, parent support interventions have a positive impact on child serving systems by facilitating collaborative relationships between families and service providers (Ireys, Devet, & Sakwa, 2002). Due to the dearth of studies examining parent to parent support in mental health, parent support in family preservation is considered. Family preservation interventions are aimed at improving child outcomes by enhancing parent capacity. Interventions have significant effects on improving children’s cognitive, social, physical, and emotional development; school performance; and safety (Layzer, Goodson, Bernstein, & Price, 2001). In addition, family support interventions have significant effects on parenting attitudes, knowledge, and behavior as well as on families’ economic self-sufficiency and overall family functioning (Layzer et al., 2001).

2.2 Kansas Outcomes

In order to examine whether children whose families received parent support had better outcomes than children whose families did not, quantitative analyses were conducted using a preexisting database from another study completed by KU (Barfield et al., 2006). Findings indicate that children whose parents received support have better outcomes on all variables than children whose parents did not. Specifically, more children whose parents were receiving support were living with their parents, had less law enforcement contact, did significantly better academically, and had better school attendance than children whose parents were not receiving support. In addition, externalizing behaviors improved more with children’s whose parents were receiving support than children whose parents were not receiving support.
3. Value & Helpfulness

3.1 Stakeholder Perspectives

The overwhelming majority of stakeholders view PSS services as an essential aspect of CMHC treatment. On questionnaires, when asked if they wanted to include additional comments about the services of their PSS, parents indicated that they respect their PSS and want it to remain an available service.

In addition, parents felt that PSS workers were great supports for parents and families; PSS provided understanding, caring, and information to assist parents in coping.

Two examples of the value communities place on their PSS stood out. At one center, a grandparent, who was the primary caretaker for two grandchildren, was sick and could not attend the focus group. This caretaker made a concerted effort to write a letter to send her message about parent support. At another center, community partners who were not asked to participate heard about the study and were especially eager to provide their input in focus groups. At this same center, direct service providers who were unable to attend the focus group sent hand-written responses to focus group questions.

On questionnaires, when PSS were asked if there was anything else they would like to say about themselves or their profession, PSS indicated that they wished the service was available when they had needed assistance. Lastly, PSS workers reported that they enjoy what they do.

3.2 Most Helpful Functions

The study identified 24 distinct roles and functions that PSS provided; however, the most helpful roles and functions that PSS performed on treatment teams (indicated in focus groups and surveys) are listed below.

3.2.1 Provide Emotional Support

This function included listening to parent concerns, affirming their feelings, and supporting their crucial roles in their children’s lives. In addition, emotional support included validating the stress of rearing children who experience SED and providing hope of recovery to parents through self-disclosure.

3.2.2 Facilitate Peer support

This function included holding family support groups that linked families with other families or resources in their communities to decrease the isolation they experienced.

3.2.3 Offer Practical Crisis Coaching

This function included being available to parents for assistance during difficult situations to discuss specific steps to manage children’s behaviors.
3.2.4 Translate Concerns and Issues

This function included talking to providers on behalf of families to address specific concerns, bridging the gap between providers and families by translating mental health terms, helping ensure families had voice in treatment planning, and helping providers understand families’ realities.

3.2.5 Establish Goal Directed or Purpose Driven Services

This function involved facilitating an understanding with treatment teams regarding the goals or purposes of the services provided to families.

3.3 Impact of Interventions on Children’s Environments

Qualitative findings indicate that PSS interventions impact the children’s environments by increasing parenting resilience, supporting parents to be involved in their children’s lives, and increasing the efficiency of the CMCH services to the entire family.

3.3.1 Improve Parenting Abilities

With regard to improving parenting abilities, parents indicate that they have increased confidence, stress management skills, peer support, and knowledge of community resources. In addition, parents become models for their children on how to manage stress and learn new parenting techniques.

3.3.2 Support Parents to Be Involved

Parent support specialists encourage parents to be involved in their children’s treatment by helping them understand how to be active in the treatment process. For instance, PSS facilitate parent involvement in goal attainment and help them understand their children’s illness as well as potential. Providers and PSS said that when parents focused on their children’s potential and engaged in goal attainment, children were more relaxed and treatment progressed at a faster rate.

3.3.4 Increase the Efficiency of Services

The main purpose of community based service is to maintain children with an SED in the least restrictive placement that will meet their needs. Functions that PSS perform increase the efficiency of CBS services to achieve this purpose. Parent support specialists do this by providing emotional support to parents which prevents the need for other services to be accessed. In addition, this support can be very effective in crisis situations to help parents manage stress or learn techniques to manage the crisis. Furthermore, PSS help support parents in navigating the school system on behalf of their children. Without this crucial support, some children would be placed in more restrictive school placements.
3.4 Unique Relationships

According to focus group findings, managing the therapeutic relationship is the key to successful treatment. On the questionnaires, PSS described a wide variety of life experiences and skills they bring to their profession. Primary among these attributes were the experiences and skills derived from parenting a child with SED. These factors afford PSS a special ability to develop a unique rapport and relationships with parents. Parents see PSS as someone who has been there and understands them, as well as the joys and challenges of living daily as parents of children with SED.

Parents reported that children notice the impact PSS has on them.

*My child tells me to call parent support, you know, that friend that helps you?*

*Parent*

4. Access

4.1 Levels of Need and Referrals for PSS Services

Despite the potential that PSS services have to enhance the overall CMHC treatment, families were generally not referred for PSS services until they experienced significant difficulties and required an intense level of support. Administrators confirmed that PSS services were reserved for families with the highest level of need. In focus groups, participants repeatedly mentioned that PSS mainly serve families with one or more of the following characteristics: single parent families, families dealing with poverty, families with youth in state custody, and parents with a developmental disability or a psychiatric diagnosis. Families of Hispanic or immigrant origin were also mentioned as a population that PSS serve. Overall, parents said they would have liked to have been referred sooner. Parent support specialists concluded that earlier referral would prevent the intense level of support they must provide upon the initial referral. Findings indicate that there are not enough PSS services available to make referrals earlier.

4.2 High Demand and Limited Supply

Caseload sizes reportedly vary from center to center (range 2 to 80) with an average of 35. Overall, participants indicated that more PSS services were needed. However, agency representatives said they did not have a way to generate enough revenue to provide the service and thus could not find a source for funding more positions. At the time of the present study, PSS services were only reimbursable through the Home and Community Based Services (HCBS)-SED Waiver. However, the majority of the work that PSS did with families was not reimbursable. Consequently, direct service staff indicated that in some agencies, families who received the HCBS-SED Waiver were prioritized referrals to PSS services. Family Centered System of Care (FCSC) funds were used to staff additional PSS positions in some agencies, while in others they were used to support supervision for PSS. Overall, findings indicate that the demand for PSS services continues to grow. Administrators said they were not able to establish more PSS positions to meet the demand because they did not generate enough revenue providing the service.
5. Challenges Integrating the Parent Support Specialist Role

The present study identified some challenges to integrating the PSS role within the treatment teams.

5.1 Clear Role Definition

Parent support specialists discussed how they must carefully define their role for themselves and the families they serve. Furthermore, PSS indicate that the component that makes them so helpful to families - the experiences PSS bring as parents of children with SED - is also what makes some PSS overzealous in their efforts to help other families. Findings indicate that effective PSS must strike a delicate balance of holding onto their passion while calmly and diplomatically assisting parents to maneuver within the system. This includes setting limits regarding how much time to spend with families and being clear about the activities PSS engage parents in. Roles were clear for PSS in agencies where all activities could be tied back to goals on the treatment plan. In other agencies, where PSS activities were not linked back to the treatment plan, some participants expressed concern that PSS would spend much more time with some families who were considered more like friends and thus had less time to serve other families.

5.2 Team Approach

Specific roles and functions were best defined when members on treatment teams were communicating regularly.

*When I’ve seen it be a really good thing is when there’s really good communication between the case manager and a parent support worker so they’re not taking the family in different directions. They’re both working in conjunction giving the family similar sorts of advice and guidance, working together, so it isn’t that they’re competing. That they’re more supporting of each other.*

Administrator

6. Training and Supervision

As identified in the literature review, training and supervision play a key role in assisting to integrate the PSS role into treatment teams. Consequently, participants said training fell short in helping PSS gain the foundational diplomacy skills needed to conduct their work as employees of a CMHC. Instead, these diplomacy skills were developed through supervision and mentoring relationships in the statewide network of PSS. Suggestions for improving training included having PSS provide the training and focusing on establishing the balance between the advocacy role and professional responsibilities PSS have as employees of a CMHC.

The majority of PSS indicated that supervision meets their needs. Supervision was instrumental in helping PSS refine diplomacy skills needed to manage relationships with parents and providers. Suggestions for improvement included helping PSS to transition
from the consumer to provider role within their agencies as well as to support the value of the PSS approach on treatment teams.

7. Benefits and Consequences of a Credentialing Program

Participants indicated credentialing could help establish parent support as a vocation, increase pay, and establish standards of work performance. Some PSS indicated credentialing may increase PSS credibility in court situations and with new parents. In addition service staff indicated that a credentialing program could provide another venue to refine skills in managing therapeutic relationships with parents.
POLICY IMPLICATIONS AND NEXT STEPS

The present study illustrates that PSS services are a valuable and effective component of the children's mental health system of care in Kansas. In looking to the future to sustain the current infrastructure of PSS services, stakeholders should consider the following steps: 1) secure funding to increase availability of parent support services; 2) target access of available parent support services; 3) continue to integrate the parent support role; and 4) continue study to understand the nature of effective parent support services within the community mental health system.

1. Funding to Increase Availability of Parent Support Services

1.1 Diversify Funding for Parent Support Services

Funding for PSS is limited in the current system of care. The present study identifies that Community Based Service (CBS) programs are not able to increase PSS staffing without more funding. Exploring ventures with other child serving systems, such as family preservation, juvenile justice, child welfare, schools and early intervention, will likely provide opportunities to increase staffing of PSS positions in communities (e.g., exploring opportunities to collaborate on foundation grants with multiple agencies or partnering with local universities to access research and grant funding). In addition, these efforts should incorporate an evaluation component to continue to document the effectiveness of PSS services across child serving systems.

1.2 Show Effectiveness of Parent Support Services

Currently, PSS services are only reimbursable through the HCBS-SED Waiver. The service has been questioned as a medically necessary service because it is not a service that specifically targets children. The present study illustrates how PSS services impact the children by enhancing parenting outcomes and the overall efficiency of the CMHC treatment process, thus improving children’s outcomes. Key findings regarding the efficacy and value of PSS services should be shared with stakeholders who have this concern.

Kansas legislators should be informed of the value and effectiveness of PSS services to sustain and possibly expand the current funding appropriated by the Children’s Cabinet via the Family Centered Systems of Care grant funding.

1.3 Collaborate to Develop Training and Program Evaluation

Collaboration can begin by continuing to disseminate information about Kansas’ innovative PSS program. Parent leaders and their partners should continue to present at national conferences and publish material regarding the effectiveness of the work PSS are doing in Kansas.

Furthermore, Kansas is in a unique situation to further establish PSS as an effective service within a community based system of care. Kansas has an established statewide training network via Wichita State University’s College of Health Professions and Kansas Social Rehabilitation Services’ Health Care Policy. The training for PSS was developed in
partnership with PSS working in the CMHC service system and is delivered by PSS. The training model parallels the service delivery approach of PSS. The PSS training represents a model of partnership recognizing parent providers' expertise and importance in the development and delivery of PSS training. The effects of this training could be explored and included in future action-based system of care evaluations of PSS services.

2. Specific Needs and Earlier Access

The present study supports that earlier access to PSS services would prevent the need for an intense level of support at the onset of the referral and has the potential to prevent crises. As more funding is pursued and identified to support PSS services, the findings from the report can be utilized to help PSS target specific needs at an earlier point in treatment with the end goal being to increase the efficiency of access to PSS services. Ways to increase the efficiency of services include utilizing the findings to develop a needs assessment, limiting caseload sizes, and incorporating realistic billable expectations.

2.1 Develop a Needs Assessment

Furthermore, the study identifies specific family situations and indicators of need for PSS services. These findings could be used to develop a needs assessment for referral to PSS services that target PSS services to meet a specific need. Along with the state service definition of PSS services, an assessment could provide a clearer distinction of the role and purpose of PSS interventions at the onset of PSS services. With a clearer role and purpose for PSS services at the onset of referral, PSS services may be more time limited.

For instance, common family situations identified in the study included the following:

- parent dealing with effects of poverty that placed her/his child at risk of out of home placement;
- parent court ordered to treatment or parent engaged with the court system on behalf of the child;
- parent of youth returning home from state custody or out of home placement;
- parent dealing with a developmental disability or psychiatric illness;
- non-English speaking parent; or
- parent who is single.

Indicators of specific need identified in the study included the following:

- parent expresses hopelessness in their child’s ability to improve;
- parent calls frequently for emotional support;
- parent has minimal social support and could benefit from peer support;
- case manager or therapist is spending the majority of their time working with the parent;
- parent could benefit from informational support or assistance with school issues; and
- parent could benefit from learning hands on parenting techniques.
2.2 Assess Caseload Sizes

This study indicates that there is a high demand and a limited supply of PSS services with caseload sizes that are high. While additional funding for PSS services are pursued and secured, caseload size limits should be assessed. Because families often come into PSS services with a high level of need for support, limits should also account for the intensity of services to be provided. For instance, along with information targeting a specific need, the initial assessment should project an estimate of amount of time to be spent providing PSS services.

2.3 Incorporate Realistic Billable Expectations

The majority of the work that PSS do is not billable to Medicaid. Thus expectations for billable hours need to account for the number of families with HCBS-SED Waiver coverage on PSS caseloads. There is also some indication that families who receive the waiver are prioritized to receive PSS services yet they may not be the families who have most need of the service. **Ideally, referral to PSS services should focus on assessment of need, not the families' ability to pay for the service.** Targeting PSS services to meet a specific need may assist with providing PSS services to families who have the most need for the services.

3. Continue Integration of the Parent Support Specialist Role

3.1 Utilize Key Findings in the Development of Training

The present study indicates that there are specific functions that PSS provide and there is a certain approach that makes PSS services effective and valuable. The PSS training should speak to these primary functions as well as how to address perspectives on the treatment teams while still advancing family driven services. In addition, the training should continue to address the development of necessary diplomacy skills needed to balance advocacy and employee roles.

3.2 Maintain Sensitive Supervision

The culture of a CMHC as well as the agencies’ commitment to family driven practice has an impact on the services that PSS provide. The present study indicates that PSS utilize supervision to develop needed diplomacy skills to manage therapeutic relationships and negotiate agency dynamics. Findings also indicate that PSS receive regular supervision and most reveal that it meets their needs. Thus, supervisors are clearly invested in PSS. However, as with any burgeoning area, some fine tuning of supervisory training could specifically address the supervisor’s crucial role in supporting and developing PSS within their CBS programs. Specifically, training could address how supervisors have a crucial role in helping other direct service staff understand the unique approach and value of PSS services. Training for supervisors could also address how they can facilitate understanding of the unique approach by encouraging a work environment that is open to constructive feedback and regular communication. In addition, the findings illustrate that regular supervision with PSS that emphasizes understanding of agency dynamics and the PSS
role within the treatment teams would also be beneficial in assisting PSS integrate within the agency.

At times you can be seen as adversarial within your own agencies. It’s a very tricky balance and the person has to be able to take supervision, to take direction so that I can make sure that she understands this tightrope that she’s walking on……You’re needing to appease two different audiences at times. They have to be able to have the ability to understand that and not feel like I’m going to be an advocate for my client no matter what. Well, that’s not the world that we live in. You’re still employed through a mental health center and you still have expectations that the employer’s going to have, that the agency’s going to have, and you can do both. She’s learned how to do both. But it takes awhile to be able to do that.

Supervisor

4. Continue Study of Effective Parent Support Services

4.1 Study Unique Relationships

The present study shows how PSS services support the transformation to a family driven system of care as well as bring a unique perspective to the therapeutic process that impacts treatment outcomes. Parent support specialists have a unique ability to develop a rapid rapport and relationship with parents because parents see PSS as someone who has been there and understands the challenges of living daily as parents of children with SED. Future study could show when and how PSS relationships are most effective to enhance parent, child, and family outcomes. For instance, future study could examine the development of the parent and PSS relationship over time and in relation to outcomes (child behavior and emotional functioning, caregiver strain, family empowerment, and goal attainment). This study would be an important initial step in establishing evidence that PSS services lead to improved child and family functioning within a community mental health system of care.

4.2 Engage Key Stakeholders in the Development of Continued Study

Parent Support Specialists and their evaluation partners can continue to work together to document and validate the family driven systems transformation. Specifically, research partners can present key findings from the present study to families, PSS, case managers, therapists, and CBS directors and gain their insights regarding the process for continued study.

4.3 Assess Cost and Children’s Outcomes

Client Status Report outcomes indicate that youth whose parents received support had a higher increase in positive functioning than youth whose parents did not receive support. For instance there was a greater change in externalizing CBCL scores for children whose parents received support than those who did not. It is possible that the PSS interventions contributed to the change in CBCL scores. For instance, by providing crisis coaching, being accessible, and listening to parents, PSS are helping to divert potential out of home
placements (e.g., psychiatric hospitalization, child welfare involvement). Furthermore, qualitative findings suggest that PSS services increase the efficiency of CMHC services by preventing the need for more services to be accessed. If parents who are receiving PSS services utilize less services overall, there may be some cost savings. A study of PSS services could be designed utilizing existing Medicaid service utilization data and CSR outcomes to assess the cost effectiveness of PSS services.
REFERENCES


REFERENCES

The Kansas Department of Social and Rehabilitation Services (FY 2005 July to March). 


Appendix A: Parent Support Specialist Focus Group Questions

Program Components and Primary Functions
1. We know you perform many services as Parent Support Specialists. What are some of the services you provide?
2. How do the services you provide relate to other service providers?
   2a. What do you do for other service providers such as CMs or therapists?
   2b. How are your services utilized by other service providers such as CMs or therapists?

Background, Training, Life Experience, Personality Traits, and Skills
1. What personal qualities do you think PSSs need to effectively perform their jobs?
   Prompts: patience, understanding, calm assertiveness
2. Are you the parent of a child or children living with SED?
3. Do you think the experience of being the parent of a child living with SED has helped you in your professional role of PSS?
   3a. How?
4. Do you think the experience of being the parent of a child living with SED has made you stronger, resilient?
   4a. How?
5. It seems like there is fine balance between having a close relationship with parents and maintaining your professional boundaries. How do you maintain your boundaries?
6. How do you balance the roles of helping families find voice (advocating) and being an employee of CMHC?
7. It seems like you do a great job of maneuvering contexts (functioning well within different environments). How do you do this?
8. How have you been able to develop good negotiating skills?
9. How do you maintain your composure under difficult situations?
10. How do you balance compassion and empathy for clients with taking care of yourself?
11. How do engage parents, build trust and rapport?
12. How do you view parents?
13. Is there anything else that you would like us to know about you, say about your backgrounds, training, life experiences, personality traits, or skills?

Services and Plans of Care
1. How are the services you provide related to the children’s plans of care?
2. I know the services you provide are covered by the family-centered system of care grant but I am confused about how this works.
For example, do you track time to be billed to this grant? If so, how? How does connecting your time to the grant work?

Value and Helpfulness of Services

1. How do the services you provide to parents help their children? (how help parents help children)
2. Any idea about what children's outcomes improve due to your work with their parents?
   2a. How would you know children are improving? What would you see that would tell you…?
3. How do you see your services being helpful to other service providers, such as CMs, therapists, attendant care workers?
4. Do you think parents value the services you provide?
   4a. How would you know?
5. Do you think other service providers value the services you provide?
   5a. If so, what services do you think they especially value?
6. Do you feel respected within the CMHC?
7. Do you have ready access to other service providers such as CMs, therapists, and the CBS director?

Education and Credentialing

1. There has been some talk about the idea of a two-year degree.
   1a. Some of you may already hold degrees. For those who do not, do you think degrees or professional credentialing would threaten the credibility you have with parents? Say your unique ability to interact with families on a peer level as someone who has “been there?”

Closure: Is there anything you would have liked us to ask that we didn’t or anything you would like to add?
Appendix B: Parent Support Specialist Questionnaire

Dear Parent Support Specialist:

As staff of the University of Kansas School of Social Welfare, we are conducting a study to learn more about Parent Support Specialists and the services you provide within the system of care. As part of this study, your input is extremely important. The information you provide will be taken seriously in decision-making processes about issues such as policy formulation and funding. We know this questionnaire will take some time to complete but would greatly appreciate your making the time to answer the questions below. No respondents or CMHCs will be identified by name. Your responses will be strictly confidential. Study findings will be presented as a whole.

1) What are the main components of your Parent Support Specialist Program, or what are the primary functions you perform for families? Please check those that apply in the table below.

<table>
<thead>
<tr>
<th>Function</th>
<th>Check</th>
<th>Function</th>
<th>Check</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advocate and inform parents about child/parent rights within the child’s school district</td>
<td></td>
<td>Do community presentations on mental health issues</td>
<td></td>
</tr>
<tr>
<td>Attend IEP meetings or other school meetings with parents</td>
<td></td>
<td>Serve as a member of community organizations and do outreach for CMHC</td>
<td></td>
</tr>
<tr>
<td>Educate and inform parents about federal and state regulations around school issues, which includes IEPs</td>
<td></td>
<td>Locate community resources to help families meet various needs</td>
<td></td>
</tr>
<tr>
<td>Hold family nights/parent support groups for parents</td>
<td></td>
<td>Talk with other service providers at the CMHC for the betterment of children and families</td>
<td></td>
</tr>
<tr>
<td>Provide parenting classes or trainings</td>
<td></td>
<td>Serve as negotiator between parents and CMHC staff to resolve issues or differences that arise</td>
<td></td>
</tr>
<tr>
<td>Provide informational workshops on subjects such as children’s diagnoses</td>
<td></td>
<td>Provide information to families about what services are available to them through the CMHC</td>
<td></td>
</tr>
</tbody>
</table>

2) Please use this space to describe any services you provide or functions you perform not listed above.

3) If you have a parent support group, how were you able to develop it?

4) How do you see the functions you perform as different from the functions case managers perform (particularly targeted case management)? Please be as specific as possible.

5) Parent Support Specialists seem very skilled at cultivating community resources, finding resources and connecting families with them. How are you able to do this?

6) Please check the box that best describes the following statements:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
<th>Do not know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generally, parents are receptive to parenting classes or training I provide</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have seen the parenting training I provide help parent improve their parenting skills, which helps their children function better (e.g., behavior).</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I could more effectively help parents if they were referred to me sooner than they are currently referred.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The person who provides my supervision is</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Statement</td>
<td>Never</td>
<td>Rarely</td>
<td>Sometimes</td>
<td>Often</td>
<td>Always</td>
<td>Do not know</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
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<td>--------</td>
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</tr>
<tr>
<td>accessible and available.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The supervision I receive meets my needs as a Parent Support Specialist.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have access to someone helpful for support.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I track my billable time.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I track the amount of time billed to the Family-Centered System of Care (FCSC) Grant.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The services I provide parents help them help their child improve the conditions for which they are receiving services at the CMHC.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The services I provide parents help them help their children accomplish the goals and objectives on their child or children’s plan(s) of care.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Generally, I feel valued and respected by other CMHC service providers.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The services I provide families increase their involvement with (or support for) their child or children’s services and other activities.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

7) Of the families you serve who have wraparound teams, on average, in approximately what percentage of instances, are you a member of the wraparound team? Please check one on table below.

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Check</th>
<th>Percentage</th>
<th>Check</th>
<th>Percentage</th>
<th>Check</th>
</tr>
</thead>
<tbody>
<tr>
<td>10-19%</td>
<td></td>
<td>50-59%</td>
<td></td>
<td>80-89%</td>
<td></td>
</tr>
<tr>
<td>20-29%</td>
<td></td>
<td>60-69%</td>
<td></td>
<td>90-100%</td>
<td></td>
</tr>
<tr>
<td>30-39%</td>
<td></td>
<td>70-79%</td>
<td></td>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>40-49%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

8) Is there an expectation within the CMHC that you have a certain number of billable hours?

Yes ______ No ______

Other (please explain)________________________________________

8a) If there is an expectation about billable hours, approximately how many hours monthly is that expectation? ____________

9) Please estimate the average number of hours you spend with families monthly and the number of those hours that are billable.

<table>
<thead>
<tr>
<th>Estimated average number of hours spent with families monthly</th>
<th>Estimated average number of hour spent with families monthly that are billable</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

10) Do you use a specific curriculum or curricula for parenting classes?

Yes _____ No _____ Sometimes _____ Does not apply _______

10a) If yes or sometimes, what is/are the name(s) of the curriculum or curricula you use (e.g., Love and Logic)?

11) Who do families usually see first when they start receiving community-based services? Please check one.

<table>
<thead>
<tr>
<th>Service Provider</th>
<th>Check</th>
<th>Service Provider</th>
<th>Check</th>
</tr>
</thead>
<tbody>
<tr>
<td>Therapist</td>
<td></td>
<td>Parent Support Specialist</td>
<td></td>
</tr>
<tr>
<td>Case Manager</td>
<td></td>
<td>Other (Please describe)</td>
<td></td>
</tr>
</tbody>
</table>
12) If someone refers families to you, who usually refers them?

<table>
<thead>
<tr>
<th>Person</th>
<th>Check</th>
<th>Service Person</th>
<th>Check</th>
</tr>
</thead>
<tbody>
<tr>
<td>Therapist</td>
<td></td>
<td>Other (Please describe)</td>
<td></td>
</tr>
<tr>
<td>Case Manager</td>
<td></td>
<td>Other (Please describe)</td>
<td></td>
</tr>
</tbody>
</table>

13) On average, approximately how long after children start receiving community based services are their parents referred to you?

14) Generally, why are families referred to you? In other words, in what situations are families referred or what is going on with families? Case examples welcome.

15) Generally, how would you describe the families you serve (i.e., families experiencing crises or who have certain needs)?

16) Please estimate the percentage of parents you serve according to the payment sources given below.

<table>
<thead>
<tr>
<th>Payment Source</th>
<th>%</th>
<th>Payment Source</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>SED Waiver</td>
<td></td>
<td>Family-Centered System of Care Grant</td>
<td></td>
</tr>
<tr>
<td>Private Pay by families</td>
<td></td>
<td>Other (Please describe)</td>
<td></td>
</tr>
</tbody>
</table>

17) How are you helpful to other CMHC direct service provider (i.e., therapists, case managers) OR How do you interact with and work with other service providers at the CMHC?

18) What life experience and/or educational background do you bring to the helping profession?

19) Please check under the category that best describes your agreement with the following statement:

The training I receive from Keys for Networking adequately prepared me for my position.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>I am neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
</table>

20) What, if any, suggestions do you have for improving the training you receive?

21) What is the title of the person who provides your supervision at the CMHC as a parent support specialist?

22) Please check the category that best describes how often you receive supervision.

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Check</th>
<th>Frequency</th>
<th>Check</th>
<th>Frequency</th>
<th>Check</th>
</tr>
</thead>
<tbody>
<tr>
<td>Twice Weekly</td>
<td></td>
<td>Weekly</td>
<td></td>
<td>Other (Please describe)</td>
<td></td>
</tr>
<tr>
<td>Every Other Week</td>
<td></td>
<td>Monthly</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

23) What, if any, suggestions do you have for improving the supervision process?

24) How long have you been a Parent Support Specialist?
25) Please check the indicator that best describes the position you hold.

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Check</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-time Parent Support Specialist with benefits</td>
<td></td>
</tr>
<tr>
<td>Full-time Parent Support Specialist without benefits</td>
<td></td>
</tr>
<tr>
<td>I serve in blended roles (PSS, case manager, wraparound facilitator)</td>
<td></td>
</tr>
<tr>
<td>Other (Please describe)</td>
<td></td>
</tr>
</tbody>
</table>

26) If you serve in blended roles, please estimate the percentage of time you spend in what roles.

<table>
<thead>
<tr>
<th>Role</th>
<th>%</th>
<th>Role</th>
<th>%</th>
<th>Role</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent Support</td>
<td></td>
<td>Attendant Care</td>
<td></td>
<td>Group Leader</td>
<td></td>
</tr>
<tr>
<td>Case Manager</td>
<td></td>
<td>Wraparound Coordinator</td>
<td></td>
<td>Other (Please list)</td>
<td></td>
</tr>
</tbody>
</table>

27) Approximately, how many families are currently on your parent support caseload?

28) How are the services you provide families related to the child or children’s plan of care (either establishing goals and/or achieving goals)?

29) How are the services you provide families related to improvement in the conditions for which the child or children is/are receiving services?

30) Please place a checkmark in the appropriate places in the tables below to let us know a little about you.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Check</th>
<th>Gender</th>
<th>Check</th>
<th>Other (Please describe)</th>
<th>Check</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td></td>
<td>Female</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Check</th>
<th>Marital Status</th>
<th>Check</th>
<th>Marital Status</th>
<th>Check</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never married</td>
<td></td>
<td>Separated</td>
<td></td>
<td>Widowed</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td></td>
<td>Divorced</td>
<td></td>
<td>Other (Please describe)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Check</th>
<th>Race/Ethnicity</th>
<th>Check</th>
<th>Race/Ethnicity</th>
<th>Check</th>
</tr>
</thead>
<tbody>
<tr>
<td>African American</td>
<td></td>
<td>First Nations</td>
<td></td>
<td>White/Caucasian</td>
<td></td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td></td>
<td>Latino/Latina</td>
<td></td>
<td>Other (Please describe)</td>
<td></td>
</tr>
</tbody>
</table>

30a) What is your age? ____________

31) Are you the parent of a child who is living with SED or who has lived with SED?

Yes _____ No _____ Other (Please describe) ____________________________

32) Is there anything else you would like others to know about you and/or your profession?

Thanks for your time and input!!!
Appendix C: Parent Focus Group Questions

**What are the specific components of a parent support program and primary roles and functions that parent support specialists perform?**

1. What services does your PSS provide for you and your family?
2. Anything you would like to see PSS do differently or in addition to what she/he is doing now?

**How do parents gain access to parent support services?**

3. What was going on in your life when you started receiving parent support services?
4. Would it have helped to have received parent support sooner than you did?

**How do the primary roles and functions parent support specialists perform differ from the functions of other service providers such as case managers?**

5. What is different about the things your PSS does and what your child’s case manager does?

**What personal characteristics, life experience, or skills do parents support specialists bring to the helping profession?**

6. How would you describe your PSS?  
   Prompt: Personality traits
7. How would you describe your relationship with your PSS?

**Staffing**

8. Case management vs. PSS turnover

**Are parent support services related to the goals on youth’s plans of care?**

9. Do you see ways your PSS helps with the goals on your child’s plan of care?

**What is the value and helpfulness of parent support services?**

10. What does your PSS do for you and your family that is especially helpful?
11. Do you have parent support group or parent night? If so, how are they helpful to you and your children?

**Are parent support services associated with improvement in the conditions for which parents are receiving community-based services?**

12. Overall, have you become more involved in your child’s life because of the parent services you receive? Or, is the quality of your involvement better?
13. What do you see in your child that tells you the parent support you receive is helping your child?
Prompt to make concrete: If I were fly on wall observing…., what would I see your child doing that would let me know they were doing better as result of receiving parent support services?

14. Do you see ways that parent support is related to keeping children in their homes as opposed to hospitalization or in SRS custody?
Appendix D: Direct Service Staff Questions

Question 2: What are the specific components of a parent support program and primary roles and functions that parent support specialists perform?
1. What functions that PSS perform seem especially important?

Question 3: How do parents gain access to parent support services?
3. Under what circumstances do parents usually start receiving parent support?

Question 5: How do the primary roles and functions Parent Support Specialists perform differ from the functions of other service providers such as case managers?
4. How do you and PSS work together? What do PSS do that helps you in your job? How do your roles complement each other?
5. Specifically, how do you see the functions PSS perform as different from those case managers perform?

Question 6: What personal characteristics, life experience, or skills do Parent Support Specialists bring to the helping profession?
6. What personal characteristics, life experience, or skills do you think PSS need in order to be effective?

Question 9: Are parent support services related to the goals on youth’s plans of care?
7. Do you see ways PSS help with the goals on children’s plans of care?

Question 11: What is the value and helpfulness of parent support services?
8. What do you value about Parent Support Specialists?
9. How do you see parent support services as helpful to the children and families?

Question 12: Are parent support services associated with improvement in the conditions for which parents are receiving community-based services?
10. In what ways do you think the services PSS provide parents lead to improved outcomes for their children?
11. Do you think parent support services increase overall parental involvement (parental support) with the children?
12. Do you see way that parent support services help maintain children in the home and community as opposed to their being hospitalized, in SRS custody, or foster care?
Question 14: What might be the benefits and consequences of Parent Support Specialists pursuing additional education and professional credentialing?

13. There has been some talk about credentialing and additional education for PSSs.

Two separate issues: 1) professional credentialing & 2) education

Do you have an opinion about the benefits and unintended consequences of these?
Appendix E: Community Partners Questions

1. What functions that Parent Support Specialists (PSSs) perform seem especially important?

2. How did you hear about parent support?

3. Under what circumstances did you started working with PSS?

4. How do you and PSS work together?
   What do PSS do that helps you in your job?
   How do your roles complement each other?

5. Specifically, how do you see the functions PSS perform as different from those case managers perform?

6. What personality characteristics, life experience, or skills do you think PSSs need in order to be effective?

7. Do you see ways parent support helps the children improve the conditions for which they are receiving mental health services? If so, how?

8. What do you value about Parent Support Specialists?

9. What do you find helpful about parent support services?

10. How are parent support services helpful to children?

11. In what ways do you see parent support services associated with maintaining children in their homes and community as opposed to being hospitalized, in SRS custody, or foster care?
Appendix F: Supervisor Questions

What training and supervision do Parent Support Specialists receive?

1. What is your job title?
2. What background and experience do you have? (education, credentials)
3. How often do you provide supervision for your PSS/PSSs?
4. What does the supervision process look like? (length of meetings, access)
5. What training does/do your PSS/PSSs receive? Do you think it is adequate?
   Keys?
   Overall, suggestions for improvement?

What are the specific components of a parent support program and primary roles and functions that Parent Support Specialists perform?

6. What do you consider some of most important functions PSSs perform?

Primary roles of PSSs and CM differ?

7. Differences between functions of CM and PSS? How unique?

What personal characteristics, life experience, or skills do Parents Support Specialists bring to the helping profession?

8. What personal characteristics, life experience, or skills do you consider important for PSSs to posses in order to be effective?

What are the dynamics surrounding staffing of parent support positions?

9. Full-time with benefits?
   9a. If part-time, what other duties perform?
10. What caseload (size) does/do your PSS/PSSs carry?

Are parent support services related to the goals on youth’s plans of care?

11. Do you see a connection between parent support services and goals on the children’s plans of care?

What billing mechanisms are utilized for parent support services?

12. Is/are your PSS/PSSs expected to track their billable time?
13. Is there an expectation about billable time? If so, what?
14. What services are Medicaid reimbursable and what services are not reimbursable under the Waiver (e.g., case conferencing is not)?
15. What percentage of parent support services are Medicaid reimbursable and what are not?
16. Can you estimate amount of time PSS spends with families and percentage that can be billed?
17. Then, the service is covered under the family-centered system of care grant. How do you keep track of hours billable to the family-centered system of care grant?

What is the value and helpfulness of parent support services?

18. Does it seem like your PSS/PSSs is/are respected within the center, among other staff members?

19. How do you see parent support services as helpful to children and families?

Are parent support services associated with improvement in the conditions for which parents are receiving community-based services?

20. How do you see parent support services provided to parents associated with improvement in the conditions of their children?

21. How do you see parent support services being related to maintaining children in the home and community as opposed to hospitalization, SRS custody, or foster care?

22. Do you track PS outcomes in any way?

What might be the benefits and consequences Parent Support Specialists pursuing additional education and professional credentialing?

23. There has been some talk about credentialing and additional education for PSSs. Two separate issues:
   A) professional credentialing
   B) education

Do you have an opinion about the benefits and unintended consequences of these?
   First professional credentialing, then education
Appendix G: Administrative Staff Questions

What are the specific components of a parent support program and primary roles and functions that parent support specialists perform?

1. What are the functions PSSs perform that you see as most important?

How do parents gain access to parent support services?

2. How do families gain access to parent support services?

What personality characteristics, life experience, or skills do PSS bring to the helping profession?

3. What personal characteristics, life experience, or skills do you consider important for PSSs to be effective?

What training and supervision do Parent Support Specialists receive?

5. What training does/do your PSS/PSSs receive? Do you think it is adequate? Overall, suggestions for improvement?

What is the value and helpfulness of parent support services?

11. Does it seem like your PSS/PSSs is/are respected within the center, among other staff members?

12. How do you see parent support services as helpful to children?

13. How see services related to goals on POC?

Are parent support services associated with improvement in the conditions for which their child or children are receiving community-based services?

14. Do you track parent support services as they relate to children's outcomes in any way?

15. Difference between CM and PSS functions? How unique?

What might be the benefits and consequences Parent Support Specialists pursuing additional education and professional credentialing?

23. There has been some talk about credentialing and additional education for PSSs. Two separate issues: 1) professional credentialing then 2) education Do you have an opinion about the benefits and unintended consequences of these?
Appendix H: Parent Questionnaire

Dear Parent,

Your opinion about the services your child or children receive(s) at the community mental health center is very important to the mental health system in the State of Kansas. The information you provide will be taken seriously in decision-making processes about issues such as policy formulation and funding. Your answers are confidential. We would greatly appreciate your taking a few moments to give feedback on the following topics:

A) Who suggested parent support services to you? Please check one.

<table>
<thead>
<tr>
<th>Person</th>
<th>Check</th>
<th>Person</th>
<th>Check</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case Manager</td>
<td></td>
<td>I saw Parent Support Specialist first.</td>
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<tr>
<td>Therapist</td>
<td></td>
<td>Other (Please explain)</td>
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<tr>
<td>School Personnel</td>
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</tbody>
</table>

B) Please respond to the following statements by checking the box that best describes your agreement.

<table>
<thead>
<tr>
<th>Statement</th>
<th>1 Strongly Disagree</th>
<th>2 Disagree</th>
<th>3 Agree</th>
<th>4 Strongly Agree</th>
<th>Does Not Apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>The parent support services I receive help me improve the condition my child is receiving services for at the mental health center.</td>
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<tr>
<td>The parent support services I receive help me to help my child achieve the goals on their plan of care from the mental health center.</td>
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<tr>
<td>The parent support services I receive help me manage my child’s behavior or symptoms.</td>
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<tr>
<td>When my parent support specialist helps with things such as school issues, ways to deal with my child’s behavior, and finding community resources, it improves our family functioning and my child’s well-being.</td>
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<tr>
<td>It would have been helpful to me and my family to have received parent support services sooner than we did.</td>
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</tbody>
</table>

C) Some functions Parents Support Specialists perform are listed below. Please indicate with a checkmark how helpful these services are in assisting you to help your child or children improve their behavior problems or symptoms.

<table>
<thead>
<tr>
<th>Function</th>
<th>1 Not Helpful</th>
<th>2 Slightly Helpful</th>
<th>3 Very Helpful</th>
<th>4 Extremely Helpful</th>
<th>Does Not Apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advocates and informs me about child/parent rights within my child’s school district</td>
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<tr>
<td>Educates and informs me about federal and state regulations around school issues, including IEPs</td>
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<tr>
<td>Attends IEP meetings or other school meetings with me</td>
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<tr>
<td>Supports me at meetings or events other than at school, such as going to court</td>
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<tr>
<td>Helps me use techniques with my child at home such as role playing or something the therapist suggested we try</td>
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<tr>
<td>Helps me cope with stress and manage my household including things like setting priorities, paying bills, and taking care of myself</td>
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<tr>
<td>Makes suggestions for managing my child’s behavior at home and elsewhere</td>
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<tr>
<td>Helps me use what I learn in workshops or parenting classes with my child in the home</td>
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</tr>
<tr>
<td>Function</td>
<td>1 Not Helpful</td>
<td>2 Slightly Helpful</td>
<td>3 Very Helpful</td>
<td>4 Extremely Helpful</td>
<td>Does Not Apply</td>
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<tr>
<td>Tells me what I can expect from other organizations such as SRS and the courts</td>
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<tr>
<td>Tells me about things at the mental health center, such as services that are available and service providers</td>
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<tr>
<td>Serves as negotiator between me and CMHC staff to resolve issues or differences that arise</td>
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<tr>
<td>Assists our family with resources in the community</td>
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<tr>
<td>Helps our family when our child is having a crisis</td>
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<td>Helps me learn ways to prevent crises with my child</td>
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<tr>
<td>Holds family nights/parent support groups for parents</td>
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<tr>
<td>Provides support for whatever reason needed, such as listening and letting me know I am not alone</td>
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<tr>
<td>Provides workshops on subjects such as childhood development and information about my child’s diagnosis</td>
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<tr>
<td>Provides parenting classes</td>
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<tr>
<td>Talks with other service providers at the mental health center for the betterment of my child/family</td>
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<tr>
<td>Talks to others on my behalf such as staff from school or other agencies</td>
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<tr>
<td>Helps me better understand what other service providers tell me, such as therapists</td>
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<td>Helps me complete paperwork like CBCLs, or for the waiver or government agencies</td>
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<tr>
<td>Supports and encourages me to have voice in my child’s case plan at the mental health center</td>
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<td>Provides transportation for me and/or my child to appointments or activities at the mental health center</td>
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<tr>
<td>Other (please describe)</td>
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<tr>
<td>Other (please describe)</td>
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</table>

D) The table below contains services your child or children may be receiving at the mental health center. These services are listed in alphabetical order. Please indicate with a checkmark how helpful these services are in assisting you to help your child improve their behavior problems or symptoms.

<table>
<thead>
<tr>
<th>Type of Service</th>
<th>1 Not Helpful</th>
<th>2 Slightly Helpful</th>
<th>3 Very Helpful</th>
<th>4 Extremely Helpful</th>
<th>Does Not Apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attendant Care</td>
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<tr>
<td>Case Management</td>
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<tr>
<td>Crisis Stabilization</td>
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<tr>
<td>Family Therapy</td>
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<tr>
<td>Home-Based Family Therapy</td>
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<tr>
<td>Individual Therapy</td>
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<tr>
<td>Medication Management</td>
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<tr>
<td>Parent Support</td>
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<tr>
<td>Psychosocial Group</td>
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<tr>
<td>Respite Care</td>
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<tr>
<td>Wraparound Meetings</td>
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<tr>
<td>Other (please describe)</td>
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</table>
The table below contains services your child or children may be receiving at the mental health center, listed in alphabetical order. Likely, many services are helpful and it may be difficult to rank only four. If you are willing, please rank the helpfulness of only four services in assisting you to help your child or children by writing 1, 2, 3, and 4 beside only four specific services. Then fill in about when you started receiving the service you ranked. Please indicate when you started receiving the services listed even if you did not rank them.

Ranking:  1 means most helpful.  3 means less helpful than 2.  
2 means less helpful than 1.  4 means less helpful than 3.

If you have any comments about any services, please enter them in the space provided by the services.

<table>
<thead>
<tr>
<th>Type of Service</th>
<th>Comments</th>
<th>Rank from 1 to 4</th>
<th>About when did you start receiving this service?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attendant Care</td>
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<tr>
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<tr>
<td>Other (Please describe)</td>
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</table>

F) Approximately when did you start receiving parent support services? _______________________

G) If you want to include additional comments about parent support services or your Parent Support Specialist, please use the space below. You may use the reverse side of this sheet if you need more space.

Thank you very much for your time and feedback!!!