
SB 44 NEEDS ASSESSMENT:

EXAMINING THE RELINQUISHMENT OF CHILDREN WITH SERIOUS EMOTIONAL DISTURBANCES

October 2014



SB 44 NEEDS ASSESSMENT: EXAMINING THE RELINQUISHMENT OF CHILDREN WITH SERIOUS EMOTIONAL DISTURBANCES

RESEARCH TEAM

Monica Faulkner, Ph.D., LMSW (Principal Investigator)

Beth Gerlach, Ph.D., LCSW (Co-Principal Investigator)

Laura Marra, MSW (Research Coordinator)

Rebecca Gomez, PhD, LCSW

Jim Schwab, Ph.D.



ACKNOWLEDGEMENTS

This needs assessment was funded by the Texas Department of Family and Protective Services and the Department of State Health Services. Points of view in this document are those of the authors and participants and do not necessarily represent the official position or policies of either department.

RECOMMENDED CITATION

Faulkner, M., Gerlach, B., Marra, L., Gomez, R. & Schwab, J. (2014). *SB 44 Needs Assessment: Examining the relinquishment of children with serious emotional disturbance*. Austin, TX: The University of Texas at Austin, Child and Family Research Institute.

EXECUTIVE SUMMARY

Roughly 5% of children are classified as having a serious emotional disturbance (Substance Abuse and Mental Health Services Administration, 2006). Children with a serious emotional disturbance may require extensive and costly medical, behavioral and educational supports. For many families, appropriate resources are difficult to locate and afford. Although exact numbers are not known, anecdotal evidence suggests that some families seek and/or are advised to relinquish the custody and care of their children to the foster care system in order to obtain mental health care for their child. In Texas, entry into the foster care system requires there to be maltreatment of the child by a caregiver. Thus, some parents face a very difficult dilemma in attempting to find help for their child.

Given this dilemma and anecdotes from families, the 83rd Texas Legislature required DFPS and DSHS to produce a study to develop recommendations to prevent parents from relinquishing custody and care of a child with a serious emotional disturbance. In order to study this issue, a joint committee from DFPS and DSHS recommended contracting with an independent researcher. The research team at the Child and Family Research Institute at The University of Texas at Austin conducted a needs assessment of families in Texas. A thorough literature review was conducted and is located in Appendix A. Interviews were conducted with parents and stakeholders. Online surveys were made available to both parents and stakeholders across the state through email listserves and websites. Findings from all interviews and surveys can be found in the appendices.

The needs assessment yielded valuable information to understand how to help families. Findings suggest that families follow very similar trajectories to get their children help. They tend to first seek help from schools and their pediatricians followed by referrals for community mental health. As behavior escalates, families often enter a cycle of calling the police for de-escalation, going to emergency rooms which result in inpatient commitments of their child. After families have experienced this cycle, they tend to question their future options and may consider or be directed towards foster care as an option. In general, families feel that services do exist to help them, but that services are difficult to obtain. The primary reason families cannot access quality services is cost. Caring for a child with a serious emotional disturbance costs families and taxpayers. Overall, the least costly options for help, such as services in schools, are often the most difficult to navigate. In most cases, services are expensive and even with insurance, families in this study reported expensive co-pays such as \$400 a month for medication or \$8,000 for just one of their child's inpatient stays. In addition to cost, there are multiple complex barriers to receiving services. Parents often spend a great deal of time and energy attempting to navigate systems to find help. While services are costly and difficult to navigate, the cost of not serving children with a serious emotional disturbance is greater. Children who are not stable are likely to enter the criminal justice system, foster care or harm themselves.

Based on the findings, the report concludes that treatment of serious emotional disturbance is a public health issue rather than a child protection issue. Additionally, while families may be able to access some services, they need access to the services most useful to them. In particular, families desired wraparound services, supportive case management, quality psychiatric services and in-

home care. Part of those services should include consultation between pediatricians and child psychiatrists in order to facilitate the appropriate care for the child. Without options for billing for consultation time, pediatricians are often left to manage the child's mental health needs without training. Despite the fact that services should be provided to prevent crises, emergency services are still needed to prevent relinquishment. Such services may include programming through the expansion of the YES program waiver which provides care to keep children in their homes. Emergency beds and collaboration between DFPS and DSHS to prevent relinquishment are also needed. Additionally, it is important that policymakers and communities treat serious emotional disturbance as a disability. Families often endure stigma and judgment as they reach out for help. This stigma may prevent children from getting much needed help. Families who seek to place their children in foster care for the purpose of receiving mental health treatment are placed on a child abuse registry. Because Texas does not have a voluntary relinquishment option, parents are either considered to have abandoned or refused to accept parental responsibility for their child. More information and options are needed regarding the child abuse registry.

Based on these findings, conclusions were presented to DFPS and DSHS for the purpose of informing their recommendations to the legislature in accordance with SB44. Those recommendations are provided in a separate document authored by DFPS and DSHS.

TABLE OF CONTENTS

EXECUTIVE SUMMARY_____	3
INTRODUCTION _____	7
BACKGROUND _____	8
Children’s mental health _____	9
The cost of mental health services _____	11
What happens when children don’t receive treatment? _____	11
Disparities _____	13
The role of health insurance _____	14
Mental health parity _____	16
Texas _____	16
Resources in Texas _____	18
Key service providers and their roles _____	21
The intersection of mental health and child welfare _____	25
Best Practices for meeting the needs of children with serious emotional disturbances _____	28
RESEARCH FINDINGS _____	35
CONCLUSIONS _____	45
REFERENCES _____	48
APPENDIX A : GLOSSARY _____	A-1
APPENDIX B: AVAILABLE SERVICES BY STATE _____	B-1
APPENDIX C: CAREGIVER SURVEY FINDINGS _____	C-1
APPENDIX D: FAMILY CASE STUDIES _____	D-1
APPENDIX E: STAKEHOLDER SURVEY FINDINGS _____	E-1
APPENDIX F: STAKEHOLDER INTERVIEWS _____	F-1
APPENDIX G: COST ANALYSIS _____	G-1

LIST OF FIGURES

Figure 1. Help seeking trajectory	36
Figure 2. Cost of not getting services	44
Figure 3. Caregiver demographics.....	C-1
Figure 4: Child demographics.....	C-2
Figure 5. Caregiver reported child behaviors.....	C-3
Figure 6. Differences in caregiver strain by relinquishment status	C-5
Figure 7. Percentage of lifetime (LT) and 12 month (12) use of common services by service type.....	C-7
Figure 8. Stakeholder participation by community type.....	E-1
Figure 9. Negative scenarios occurring “often or always”	E-2
Figure 10. Positive scenarios occurring “sometimes” and “often or always”	E-3
Figure 11: Scenarios where foster care may be considered a reasonable option.....	E-4
Figure 12. Percentage indicating “enough providers in area” by service type	E-5
Figure 13. Taxpayer costs of caring for a child with serious emotional disturbance	G-1
Figure 14. Estimated DFPS costs of caring for child with serious emotional disturbance	G-2

LIST OF TABLES

Table 1. Family support programs by state.....	30
Table 2. Benefits of different services.....	38
Table 3. Cost to families and taxpayers	41
Table 4. Barriers to obtaining services/ Common problems with services	42
Table 5. Available services by state	B-2
Table 6: Child insurance over the past 12 months	C-2
Table 7. Behavior categories and descriptions.....	C-3
Table 8. Mean scores on objective and subjective internalizing strain	C-4
Table 9. Percentage of lifetime and 12 month service use by service type	C-5
Table 10. Services never attempted to be used by at least 75% of caregivers.....	C-8
Table 11. Percentage of caregivers indicating ‘yes’ to each barrier.....	C-10
Table 12. Identified barriers and needs of caregivers	C-11
Table 13. Stakeholder participation by years of experience.....	E-1
Table 14. Service affordability and accessibility ranked by usefulness.....	E-6
Table 15. Number and percentage of cases by case criteria	E-4
Table 16. Costs of services for youth in YES waiver program.....	E-5

INTRODUCTION

In order to fulfill the obligations for SB44 from the 83rd Legislative Session, DFPS and DSHS contracted with the Child and Family Research Institute at The University of Texas at Austin to conduct a needs assessment regarding the needs of families and children with a serious emotional disturbance to prevent the relinquishment of custody and care of these children to the foster care system. The agencies requested three specific elements be included in the study. These elements include: 1) an exploration of best practices in other states; 2) analysis of the current practices and resources in Texas; and 3) a cost benefit analysis of alternatives which may prevent relinquishment.

An extensive literature review including information about best practices in other states is included in Appendices A and C. In general, other states are creating programs to prevent relinquishment. However, as these efforts have not been evaluated, determining best practices is premature. Thus, the research team developed a needs assessment methodology that would explore best practices according to professionals and families. The needs assessment also obtained information about the current practices in Texas and various costs associated with serving children with serious emotional disturbances.

The needs assessment consisted of five components. These included:

- 1) interviews with ten stakeholders which included pediatricians, mental health policy associates, advocacy agencies, mental health policy analysts, researchers, psychologists, and psychiatrists;
- 2) An online survey completed by 31 stakeholders who were primarily social workers;
- 3) Case studies of five families with children with serious emotional disturbances;
- 4) An online survey completed by 28 parents and caregivers of a child with a serious emotional disturbance; and
- 5) A cost analysis of caring for a child with a serious emotional disturbance.

The needs assessment was conducted during the Spring of 2014. Information from all components were used to develop the main findings and conclusions presented in this report.

BACKGROUND

In 2000, the Surgeon General identified children’s mental health needs as a national health crisis. Children’s mental health disorders are frequently unidentified or are identified too late. Families struggle with multiple barriers to getting their children the services they need. These include service and payment systems that are overly complex, fragmented service delivery systems, provider shortages, and low payment rates. When families are able to access services for their children, the service delivery systems often fail to offer the full range of services needed and children may not receive services in a timely manner. Children may not be identified and may not receive services until serious problems have developed. When faced with a mental health crisis, families may find no alternative to relinquishing their child to state custody in order to access mental health services.

Although most states do not collect and report information on relinquishment, it is estimated that nearly a quarter of children with a serious emotional disorder are relinquished to state child welfare systems, while another quarter enter juvenile justice systems (National Alliance for the Mentally Ill, 1999). It should be noted that this statistic is from a non-nationally representative sample and should not be used cautiously as more research is needed to verify this statistic. Middle class families are at high risk of relinquishment because these families do not qualify for Medicaid. A serious emotional disorder can exhaust private insurance coverage and many insurance plans will not cover the level of care needed.

Relinquishment has dramatic consequences for families and children. Relinquishing custody can be emotionally devastating for families. Parents are excluded from their role in planning and making choices to guide their child’s life. Children’s mental health issues may be exacerbated by the instability and confusion that relinquishment creates, and they may experience feelings of abandonment. The choice between parenting their child and the receipt of desperately needed treatment is one no family should have to make.

- ◆ There are no nationally representative statistics on the numbers of children relinquished into foster care for the purposes of receiving mental health treatment.
- ◆ States have not consistently tracked numbers of children who enter foster care to receive mental health treatment.

Children's mental health

It is estimated that children with SED comprise 5% of the total child population (SAMHSA, 2006). Further, it is estimated that by the year 2020 neuropsychiatric disorders in children will rise by 50% and become one of the most common causes of mortality among children (WHO, 2001). Seventy-nine percent of children between the ages 6 and 17 in need of mental health services do not receive needed services (Kataoka, Zhang, & Wells, 2002). Poverty is a risk factor for mental health disorders in children (Howell, 2004; McLearn, Knitzer, & Carter, 2007; National Center for Children in Poverty, 2006), but despite the high need, children in low-income families are least likely to utilize services (National Center for Children in Poverty, 2006). Low-income children are more likely to be exposed to environmental stressors, such as community and family violence, which are predictors of poor mental health outcomes (Buckner, Beardslee, & Bassuk, 2004; McLearn et al., 2007). Parental stress, such as financial and emotional difficulties, can impact parenting which subsequently impacts children's mental health (Aber, Jones, & Cohen, 2000; Fraser, 2006; Gershoff, Aber, Ravr, & Lennon, 2007; Knitzer & Cohen, 2007).

Children with
SED comprise 5%
of the child
population

(SAMHSA, 2006)

Utilization of mental health services can be predicted by demographic characteristics. Boys are more likely to use mental health services than girls. Additionally, children are more likely to utilize services as they age, with older children also experiencing more restrictive types of treatment. Furthermore, children who exhibit externalizing behaviors receive more services than those with internalizing behaviors (Brannan, Craig, Heflinger, & Foster, 2006). Externalizing behaviors might include physical aggression, destruction of property or running away from home while internalizing behaviors may include social withdrawal, changes in sleeping or eating patterns or difficulty concentrating.

Mildly impaired

Half of children who have a mental health disorder that impedes their ability to live and learn are mildly impaired. Children with mild impairment may not be readily identifiable. Their impairment may affect school and relationships. Although these children would benefit from treatment, they may be able to function if environmental stressors are limited.

Significantly impaired

Unlike children with mild impairments, children who are significantly impaired have disorders that are readily observable. They have observable difficulties in home, school, and social situations. These children display either a high level of internalizing or externalizing behaviors. These children need some form of mental health services and may need additional help in school (Koppelman, 2004).

Serious emotional disturbance

Half of the children who are significantly impaired (approximately 5% of all children) are severely affected by their mental health disorder. These children are labeled as having a severe or serious emotional disturbance. The Substance Abuse and Mental Health Services Administration reports that 43% of these children have disruptive disorders, 35% have depression and anxiety, and 33% have more than one diagnosis (SAMHSA, 2006). These

children are at high risk for poor outcomes, including a 50% high school drop-out rate and a subsequent high arrest rate (President's Commission on Excellence in Special Education, 2002). Caring for children with a serious emotional disturbance requires a range of services including: medication, respite, individual and family therapy, classroom support, and may require partial hospitalization or residential treatment (Koppelman, 2004).

A review of the Child and Family Service Reviews (CFSR) highlights that the majority of states struggle to address children's mental health needs. In 2003, a review of the CFSRs revealed that in 31 states children did not receive adequate services to meet physical and mental health needs. Thirty states were rated as needing improvement in the area of "mental health of the child". Common concerns identified across all areas of mental health included inadequate availability of mental health services and concerns about the quality of services. Additionally, states did not consistently provide mental health assessments to children. States were also inconsistent in providing services to children and parents. Another concern identified across states is that caregivers and children are not regularly included in case planning. Finally, the review showed that states have a shortage of placement options for children with developmental disabilities and behavioral problems. Overall, states performed poorly on indicators of mental health when compared to other indicators (McCarthy, Marshall, Irvine, & Jay, 2004).

Estimating the number of children who are relinquished in order to receive services for a serious emotional disturbance is challenging. Many states do not collect or report this data. The General Accounting Office (2003) found that 12,700 children were placed in either the child welfare system or juvenile justice system in order to receive mental health services. These numbers underestimate the need, as 31 states did not provide data (United States General Accounting Office, 2003). The President's New Freedom Commission on Mental Health reported that approximately 4-9% of children in the United

States have a serious emotional disturbance (The President's New Freedom Commission, 2003). It is unknown how many children with serious emotional disturbance are placed in foster care for the purposes of receiving mental health treatment. One study conducted by The National Alliance for the Mentally Ill, an advocacy group, suggested that approximately one-fifth of children with a serious emotional disorder are relinquished (NAMI, 1999). However, this estimate was based on a non-representative sample of parents who responded to the survey. With limited information available about the study's methods, the estimate is should be used cautiously. The consequences of relinquishment are great. Relinquishment not only comes at a great financial cost to state child welfare systems, it has a tragic emotional and psychological cost for families and children. Relinquishing custody means that parents are no longer able to make or plan important life choices for their children (Bazelon, 2003). Relinquishment creates instability, confusion, and feelings of abandonment for already vulnerable children (Bazelon, 2003; Simmons, 2008).

The cost of mental health services

Data from the National Survey of Children with Special Health Care Needs found that the most frequently cited reasons parents gave for children having unmet mental health needs were cost and problems with their health insurance plan (DeRigne, 2010). Although the overall cost of mental health services may be difficult to capture and tend to be conservative estimates, scholars do have estimates that shed light on the challenges of financing care. In 1996, 8% of health care spending in the United States went to mental health services, including 69 billion dollars in direct costs for the treatment of mental illness (U.S. Department of Health and Human Services, 1999). In 1998, over 11 billion dollars was spent on mental health care for children and adolescents specifically with over 60% of spending going to treatment for adolescents (Ringel, & Sturm, 2001). Although the estimates of the cost of mental health services for children and adolescents are high, the cost of untreated mental health issues is even higher. These costs include: loss of life, incarceration, and loss of productivity. Untreated mental illness costs \$105 billion in lost productivity each year as well as \$8 billion in crime and welfare expenditures (National Mental Health Association, 2001).

Because mental health issues tend to manifest early in life (U.S. Department of Health and Human Services, 1999; Rupp, Gause, & Regier, 1998), children experience a cumulative disadvantage as they age. Losses to the individual, family, and community increase over time as the illness continues to affect their functioning in school, employment, and relationships (U.S. Department of Health and Human Services, 1999; Rupp, Gause, & Regier, 1998). Early intervention with effective treatment is critical to decrease individual and community losses and prevent chronic mental health disorders (Kessler, Berglund, & Demler, 2005).

What happens when children don't receive treatment?

Healthy development is contingent on good mental health (Kapphahn, C., Morreale, M., Rickert, V.I., & Walker, L., 2006). Mental health is critical to relationships, personal well-being, and the ability to contribute to the community (U.S. Department of Health and Human Services, 1999). Eighty percent of youth with mental illness do not receive treatment (U.S. Department of Health and Human Services, 1999). The outcome of untreated mental health issues can be devastating. Suicide is the third leading cause of death in children between the ages of 15 and 24 (CDC, 2014), and 90% of children and adolescents who commit suicide have a mental health disorder (Institute of Medicine, 2002). Additionally, 65% of boys and 75% of girls in juvenile detention have an untreated psychiatric disorder (Teplin, 2002).

Research has firmly established the importance and effectiveness of appropriate and timely treatment of mental health issues in children (Zito, Safer, & DosReis, 2002; Olfson, Shaffer, & Marcus, 2003); however, it is well documented that children are not getting timely treatment (Wang, Berglund, & Olfson, 2005). Early onset of mental health conditions is a risk factor for delayed treatment. Delays in treatment have been estimated to be as high as 23 years after onset, meaning that a child who had the onset of a mental health condition at age five may not receive treatment until they were 28 years old (Wang, Berglund, & Olfson, 2005).

Untreated mental health disorders also put children at risk of involvement with the juvenile justice system. Research strongly documents a link between mental health disorders and involvement in the juvenile justice system (Domalanta,Risser, Roberts, & Risser, 2003; Teplin, Abram, McClelland, Dulcan, & Mericle, 2002; Vermeiren, 2003; Wasserman, Ko, & McReynolds, 2004). Among incarcerated youth, rates of externalizing behaviors are as high as 72% while rates of internalizing behaviors are as high as 33% (Teplin et al., 2002; Vermeiren, 2003). The high rates of mental health disorders among children in juvenile justice facilities is particularly alarming given that these facilities are unlikely to screen for mental health disorders or to provide appropriate treatment (Boesky, 2002; Coccozza, & Skowyra, 2000; Teplin et al., 2002). Left untreated, mental health disorders are likely to become worse. Juvenile justice settings increase the likelihood for progression of disorders due to the risk of isolation, victimization, and fear (Ginsburg, & Demeranville, 2001; Thompson, 2004). In addition to the high human cost, the financial cost of incarcerating youth with mental health disorders is also high. It is estimated that the cost of one year of incarceration is \$35,000 per youth (National Health Policy Forum, 2004).

Children with untreated mental health disorders are also at risk educationally. Children with serious emotional disturbances have the highest drop-out rate when compared to children with other disabilities (National Health Policy Forum, 2004).

Costs of untreated mental health

- ◆ Untreated and mistreated mental illness costs the United States \$105 billion in lost productivity and \$8 billion in crime and welfare expenditures each year.

(National Mental Health Association, 2001)



Disparities

Disparities in mental health services exist between racial and ethnic groups (U.S. Public Health Service, 2001). Non-white racial and ethnic groups are less likely to receive care, and when they do receive care, they are likely to receive lower quality services (The President's New Freedom Commission on Mental Health, 2003; United States Public Health Services Office of the Surgeon General, 2001). African-American and Latino children are more likely to have their mental health needs unmet when compared to other children (The President's New Freedom Commission on Mental Health, 2003). A separate study found that among Hispanic children with identified mental health needs, these needs went unmet for 86% of these children compared to 78% of black children and 69% of white children (Ringel, & Sturm, 2001). Further, low income children have both the highest need of mental health services and highest rate of unmet needs (U.S. Department of Health Service, 1999; Sturm, Ringel, & Andreyeva, 2003).

Children in rural areas are also at increased risk. Rural areas often lack providers who can provide mental health treatment. Children in rural areas require more expensive treatment and present symptoms of greater severity while facing increased delays in treatment when compared to their urban peers (The President's New Freedom Commission on Mental Health, 2003). Additionally, certain populations of children including those in foster care, the criminal justice system, and special education programs, are more likely to have mental health issues that require services compared to children not involved in those systems (U.S. Public Health Service, 2001; Hazen, Hough, Landsverk, & Wood, 2004; Zima, Bussing, Yang, & Belin, 2000). Also at increased risk are children with special health care needs (Stein, 2011; Warfield, & Gulley, 2005).



Racial and ethnic mental health disparities

- ◆ Non-white racial ethnic groups are less likely to receive care
- ◆ When they do receive care, they are less likely to receive quality services

President's New Freedom Commission on Mental Health, 2003;
United States Public Health Services Office of the Surgeon General, 2001

The role of health insurance

In general, children who are insured have greater access to health care services than uninsured children (Newacheck, Hughes, McManus, Fox, Hung, & Halfon, 2000; Society for Adolescent Medicine, 2004). Children without health insurance are less likely to use services than children who have coverage (Busch, & Barry, 2007). Additionally, data show that children enrolled in a state run children's health insurance program (CHIP) have more mental health needs met after enrollment in the program compared to before the program (Feinberg, Swartz, Zaslavsky, Gardner, & Walker, 2002; Fox, Moore, Davis, & Heintzelman, 2003; Szilagyi, Shenkman, Brach, LaClari, Swigonski, & Dick, 2003). Texas tends to have the highest numbers of uninsured children in the nation. In 2002 it was estimated that over 20% of children received coverage from public health insurance programs (i.e. Medicaid and SCHIP), a little over 1% of children were covered under both public and private plans, and over 12% had no coverage (Newacheck, Park, Brindis, Biehl & Irwin, 2004).

Private Insurance

Data from the National Survey of Children with Special Health Care Needs found that 27% of parents who had children covered under a private health insurance plan reported that their child had mental health needs that went unmet due to the services being too expensive, compared to only 11.7% of parents whose children were covered under a public health insurance plan (DeRigne, 2010). Further, 26% of parents whose children were covered under a private health insurance plan reported problems with the health plan as the reason that their child's mental health needs went unmet, compared to 13.8% of parents whose children were covered under public health insurance. The majority of children in the United States receive mental health coverage through a parent's employer based plan or through private purchase insurance. Private insurance plans vary in the coverage of mental health services but many provide a limited number of outpatient visits and hospital days. In an analysis of 98 of the most common HMO and PPO health plans, it was found that 20% of the plans did not cover prescription drug benefits, 20% offered prescription drug benefits but not to those with behavioral disorders, and more than 20% of the plans excluded residential treatment and partial hospitalization (Koppelman, 2004). The limits imposed by private insurance plans



may not provide adequate coverage to address the needs of children with serious mental health challenges (Bazelon, 2000, & Newacheck, Park, & Brindis, 2004).

Medicaid

Approximately 20% of children with a mental health diagnosis are publicly insured with the majority being insured under Medicaid (Koppelman, 2004). Although children covered by Medicaid are entitled to needed mental health services, states vary in their implementation of mental health services. In addition, mental health providers, including residential treatment providers, may choose not to accept state Medicaid reimbursement (Bazelon Center for Mental Health Law, 2000). Children may receive benefits through traditional Medicaid or through Medicaid expansion programs. Federal law entitles children to a range of mental health services under Medicaid including Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) to children under 21 (Medicaid and CHIP Payment and Access Commission, 2012). The role of EPSDT is to identify both physical and mental health problems and provide needed services. In Texas, these services are provided under the Texas Health Steps Program (Texas Department of State Health Services, 2014a). The law entitles Medicaid-eligible children to any necessary care, services, and treatment including mental health care. Despite this law, many children do not receive services because screenings do not occur in a timely manner (National Health Law Program, 2002; Children's Defense Fund, 2005). Barriers to care include limited access to providers, incorrect beneficiary contact information, and failure of beneficiaries to keep appointments (U.S. Department of Health and Human Services, 2010).

State Children's Health Insurance Program

The State Children's Health Insurance Program passed in 1997 provides states with funds to extend health coverage to children who exceed the income limits of Medicaid. These plans may not cover the full range of mental health services. States have the option to either expand their Medicaid program or to designate an alternate plan. State plans may not provide the range of mental health services necessary for children with serious mental health needs (Bazelon Center for Mental Health Law, 2000). The state specific Child Health Insurance Program (SCHIP) may provide less comprehensive services than Medicaid or Medicaid expansion programs. In state specific SCHIP plans, states do not have to meet the comprehensive benefits package of Medicaid but instead have latitude in determining their own benefits (Brindis, Morreale, & English, 2003). Most states chose to provide benchmark equivalent coverage that is equal to either government employee insurance benefits or the benefits of the state's largest commercial health maintenance organization. Available data suggest that the mental health benefits in SCHIP plans may be limited with restrictions including limits on the number of outpatient and inpatient visits permitted and high cost-sharing for the patient (Bazelon Center for Mental Health Law, 2003; Brindis, Morreale, & English, 2003; Fox, McManus, & Limb, 2003).

Children receiving services through the publicly funded programs of Medicaid and State Children's Health Insurance Programs utilize greater services than those in private insurance plans. This discrepancy can be attributed to both the high need among these children and the greater inclusion of mental health services in publicly funded plans (Ringel, & Sturm, 1998).

Minority children are disproportionately insured under public plans. Despite families' reliance on these programs, many states have taken measures to cut these programs. Cost cutting measures include: reduced benefits, restricting eligibility, increasing patient cost, and cutting reimbursement to providers (Bazelon Center for Mental Health Law, 2003; Morreale, & English, 2003). Cuts to public healthcare systems have a negative impact on children with mental health needs. While these cuts may result in short-term saving for states, they have the potential for large long term costs as untreated mental health issues become more severe (Bazelon Center for Mental Health Law, 2003). How these trends impact children in Texas is explored further below.

Mental health parity

The Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA) was enacted on October 3, 2008. MHPAEA supplemented the Mental Health Parity Act of 1996. The Mental Health Parity Act of 1996 required parity lifetime and annual dollar limits for mental health and medical benefits. MHPAEA extended this to include substance use disorders. MHPAEA requires group health plans and health insurance issuers to ensure that financial requirements (such as co-pays, deductibles) and treatment limitations (such as visit limits) applied to mental health or substance use disorder treatment are the same as other medical benefits in the plan. The Act applies to private and public employers with more than 50 employees. Although MHPAEA requires the mental health and substance abuse disorders be covered to the same extent as medical benefits, it only applies to carriers who cover all of these services. Health plans are not required to provide mental health and substance use disorder benefits.

Mental Health Parity and Addiction Equity Act of 2008

- ◆ The law requires that any group health plan that covers more than 50 employees and offers mental health and/or substance use disorders coverage must provide that coverage with no greater financial requirements or treatment limitations than the predominant requirements the plan applies to substantially all medical / surgical benefits
- ◆ The law does NOT require employers to cover mental health or substance use treatments if they are not already offered


(MHPAEA, Pub. L. 110-343)

Texas

The 83rd Legislature increased children’s mental health funding in Texas by 59%. Increased budget allocations were made to continue to expand the YES Waiver Program, eliminate existing waitlists for mental health services and train educators in mental health first aid. Prior to this session, the legislature had not increased funding to most health and human services in the 82nd Legislature.

Texas began focusing on mental health in 1991 when the Texas Legislature established the Children’s Mental Health Plan in 1991 and targeted funding for children’s mental health. In 1995, the 74th Texas Legislature mandated the Texas Department of Mental Health and Mental Retardation, in conjunction with key stakeholders, to develop a plan to address the issue of Texas children being relinquished to the state to receive needed residential treatment for mental health concerns (Texas Department of Mental Health and Mental Retardation, 1996). That plan attempted to establish intensive community-based mental health service for children in Texas. However, the plan did not fund residential treatment services. At that time, it is reported that over 250 families relinquished their children to the custody of the State of Texas in order to receive residential treatment services. This phenomenon resulted in the creation of recommendations to expand access to residential treatment for Texas children.

Children in Texas are less likely than children in other states to receive needed mental health services (Kaiser Family Foundation, 2007). It is estimated that less than 33% of the children in Texas with a severe emotional disturbance receive community mental health services (Texas Department of State Health Services, 2014b). Low income children are at increased risk of not receiving mental health treatment and less than 33% of the doctors in Texas accept Medicaid (Hogg Foundation for Mental Health, 2012). In 2009, 68% of Texas counties were identified as having a shortage of mental health providers (Hogg Foundation for Mental Health, 2012). It is estimated that over 1 million children in Texas do not have health insurance and these children are likely to rely on crisis services (Children’s Defense Fund, 2014).



Estimated that less than **33%** of the children in Texas with a SED receive community mental health

Resources in Texas

Although Texas does not officially track and record the number of children who are relinquished due to mental health needs, in 2008, 300 children entering state care under the disposition “refusal to accept parental responsibility” had documented disabling emotional problems (Texas Department of Family and Protective Services, 2010). Texas does not have a mechanism for relinquishment solely to obtain mental health services. The state also does not specifically track the number of children who enter care because the family is unable to access mental health services. Children must enter the system under a determination of abuse and neglect, resulting in many of the children who are relinquished in an effort to get mental health services entering under the disposition “refusal to accept parental responsibility.” Some children may be relinquished because private insurance plans do not cover the level of care needed (Children’s Hospital Association of Texas, 2006). In general, the numbers of children relinquished due to mental health treatment needs is unknown and largely based on estimates extrapolated from DFPS and DSHS data systems.

Health and Human Services Commission (HHSC)

The HHSC is responsible for running both Medicaid and the Texas Children’s Health Insurance Program which provide mental health services to qualified children in the state of Texas. HHSC was also responsible for the Texas Integrated Funding Initiative (TIFI), now the Texas Systems of Care Steering Committee and Community Resource Coordination Groups (CRCGs). CRCGs operate in every county in Texas and coordinate individual service plans for children while the TIFI, now the Systems of Care Consortium, supports a system of care approach piloted in 4 communities (Children’s Hospital Association of Texas, 2006). Although CRCGs are available to youth across Texas, they are established and facilitated on a county-by-county basis. CRCGs do not receive state funding for coordination activities. Thus, the resources available to families greatly vary.

Department of State Health Services (DSHS)

Within the Department of State Health Services, the Mental Health and Substance Abuse Services Division is responsible for overseeing state hospitals and local mental health authorities (LMHAs). LMHAs receive funding from DSHS and other sources. They have contracts with 37 Community Mental Health Centers and the Dallas Area NorthSTAR Authority. While LMHAs are available, they often have limited capacity due to shortages of providers. As a result, services that might prevent crises often necessitate placement on waitlists.

Inpatient and residential services are provided by state hospitals and the Waco Center for Youth. The Waco Center for Youth is the only residential treatment center owned by the state that serves youth (Children’s Hospital Association of Texas, 2006). The Waco Center for Youth serves ages 13-17 and has 75 beds. It generally has a waiting list.

Department of Family and Protective Services (DFPS)

Two divisions of DFPS are involved with mental health services for children. These are Child Protective Services and Prevention and Early Intervention. Child Protective Services provides services to children and families who have experienced or are identified as at-risk for child abuse and neglect. Prevention and Early Intervention runs the Services to At-Risk Youth Program which contracts for some mental health services.

Department of Assistive and Rehabilitative Services

The Early Childhood Intervention Division under (DARS) serves children under three years of age who have disabilities or developmental delays. Under this program children under three with significant disabilities and/or developmental delays may receive mental health services if needed.

School Districts

Children receive a variety of mental health services through Texas public schools. Children diagnosed with a severe emotional disturbance may receive services through special education, while children with less serious disturbances may receive services through the Communities in School program. However, the quality and accessibility of programs differ by school and school district depending on the resources available and the level of community commitment to addressing mental health needs.

Texas Juvenile Justice Department (TJJD)

The 82nd Texas Legislature created the Texas Juvenile Justice Department (TJJD). The previous operations of the Texas Juvenile Probation Commission and the Texas Youth Commission were transferred to the TJJD. The Texas Juvenile Justice Department has the ability to provide mental health services based on court orders and funding availability. TJJD also operate the Special Needs Diversionary Program (described below) which provides treatment to youth with serious mental impairments (Texas Juvenile Justice Department, 2014). Prior to consolidation into the TJJD the Texas Youth Commission (TYC) noted an increase in number and severity of mental health needs among offenders. From 1997 to 2004, the number of youth with a diagnosed mental health condition increased by 16% (Texas Juvenile Justice Department, 2014).

Special Needs Diversionary Program (SNDP)

In 2001, the Texas legislature created the Special Needs Diversionary Program (SNDP). SNDP provides mental health treatment supervision. The program is administered by both the Texas Juvenile Justice Department (TJJD) and the Texas Correctional Office on Offenders with Medical and Mental Impairments (TCOOMMI) (Texas Juvenile Justice Department, 2014).

SNDP combined probation officers with mental health staff. The two collaborate to provide intensive case management. Youth are provided mental health services, probation services and education. SNDP requires frequent contact with youth and small caseloads (Texas Juvenile Justice Department, 2014).

In 2011 (FY) it is estimated that 38.5% of the youth under the supervision of the Texas Juvenile Justice Department had a mental illness. Only 40% of these youth received services as the SNDP program only served 1,410 youth in 2011. The most frequently occurring diagnoses for youth served under SNDP are Attention Deficit Hyperactivity Disorder, Oppositional Defiant Disorder, and Other Mood Disorder. Additionally, 14% of youth served had both a mental health diagnosis and a substance abuse diagnosis (Texas Juvenile Justice Department, 2014).

Youth Empowerment Services Program (YES)

The YES Waiver was adopted following concerns about parents relinquishing custody of children with a serious emotional disturbance after having exhausted all of their resources. The Health and Human Services Commission and Department of State Health Services implemented the 1915(c) Medicaid Waiver following federal approval. The Youth Empowerment Services (YES) waiver provides services for children with serious emotional disturbances by allowing increased flexibility in funding community-based services. The YES Waiver reduces the cost of Medicaid funded inpatient psychiatric expenses by providing children with community-based services. The program has four goals: provide a complete continuum of community-based services, reduce inpatient psychiatric hospitalization, prevent entry into the child welfare system, and improve outcomes for children and families (Texas Department of State Health Services, 2014b).

The YES waiver was originally piloted in Bexar and Travis Counties with an expansion to Tarrant County in 2012. The program serves a maximum of 400 children between the ages of 3 and 18. Eligibility is determined using criteria for Medicaid psychiatric hospitalization and does not consider parental income. Eliminating parental income from calculations removed the need for parents to relinquish in order to access Medicaid covered treatment. In addition to traditional services, YES Waiver recipients may receive supportive services such as respite care, transitional services, adaptive supports, transportation, home modifications, and employment services (Texas Department of State Health Services, 2014b).

An evaluation of the initial pilot of the YES Waiver program showed improved outcomes. The youth served by the program showed significant improvement in emotional and behavior problems. Youth who participated in the program also displayed a decrease in rates of inpatient hospitalization and a decrease in the number of days of hospitalization. Evaluation showed that both parent and youth had positive perceptions of the program. Parents reported the program was strengths-based, culturally and linguistically competent, engaging, provided hope, provided them a voice, helped families form a support network, and focused on individualized life goals. Community providers and stakeholders also had positive perceptions of the program and identified important components of the program to be: access to Medicaid, wraparound planning, and the availability of nontraditional services and supports (Texas Institute for Excellence in Mental Health, 2012).



Crossover Youth

It is important to note that although the above agencies represent discrete categories of service, a number of youth cross over systems of care. The risk factors associated with children who have experienced abuse and neglect are impacted by mental health challenges and interact with the juvenile justice system. This results in many children crossing over systems of care. Although not all youth with mental health disorders are crossover youth, the majority of crossover youth have a mental health disorder. Crossover youth are at risk for disruption of services as they transition across systems. These youth require increased coordination of care which results in increased treatment costs (Bilchik & Nash, 2008).

Key service providers and their roles

Currently, there are not enough professionals and services to provide the assistance needed for children with serious mental health challenges (Annapolis Coalition on Behavioral Health Workforce, 2007).

The Role of Family Advocacy, Support, and Education Organizations

Five major national organizations have a role in supporting families of children with mental health challenges. These include: The National Alliance for the Mentally Ill (NAMI), Mental Health America, the Federation of Families for Children's Mental Health, Children and Attention Deficit/Hyperactivity Disorder, and the Child and Adolescent Bipolar Foundation (Hoagwood, Green, Kelleher, Schoenwald, Rolls-Reutz, Landsverk, Glisson, & Mayberg, 2008). The development of family support and advocacy in the area of children's mental health has been credited with the expansion of community-based services (Hoagwood et al., 2008). A national survey of these organizations found that the key advocacy issues for them were public awareness of mental health and family involvement (Hoagwood et al., 2008). These agencies provide an important role in providing information and referrals to family members. A survey of these organizations rated the availability of services as the most important factor in improving children's mental health (Hoagwood et al., 2008).

Crisis Services

Research conducted by the Maryland Coalition of Families assessing the utilization of crisis services in Maryland, Georgia, and Wyoming found that 77% of families of children with mental health needs utilized crisis services (Geddes, & Walker, 2003). Families utilized crisis services when their children exhibited out of control behavior, and the behaviors were perceived as threatening and violent (Geddes, & Walker, 2003). Further, families in the study reported that their children were often dangerous to themselves. Seventy-seven percent of families reported out of control behavior, 47% reported that their child was a danger to themselves, 47% reported their child was a danger to others, and 33% report their child had suicidal ideations (Geddes, & Walker, 2003). The most frequently utilized crisis service was the emergency room (85%) followed by law enforcement (28%) (Geddes, & Walker, 2003).

◆ 77% of families of children utilized crisis services

◆ Emergency rooms (85%) and law enforcement (28%) used most often

(Geddes, & Walker, 2003)



Emergency Departments

Although families reported the emergency room as the most frequently utilized service in a crisis, they reported emergency departments as not being helpful. One major challenge of utilizing hospital emergency rooms was transportation. Fifty-one percent of families reported transporting their child to the emergency room themselves, despite the fact that this posed a safety risk. Sixty-eight percent of the families who had their children transported to the emergency room by law enforcement reported that their child was handcuffed, and it was traumatic for the child. This experience made families reluctant to contact law enforcement (Geddes, & Walker, 2003).

In addition to transportation issues, families reported other challenges to emergency room utilization. They reported long waits, being treated with judgment, and not being listened to by staff. Families experienced long wait times for their child to be assessed and also reported their child staying in the emergency department for days while waiting on an inpatient bed. Further, hospital policies often prohibit families from leaving their child unattended in the emergency room. This means that while waiting for an inpatient bed, families were unable to leave to care for other children in the family. Overall, 58% of the families surveyed in the Maryland Coalition of Families survey reported that the emergency room was not helpful (Geddes, & Walker, 2003).

Law Enforcement

Law enforcement was another service utilized by families experiencing a mental health crisis. Families are often directed by agencies and private practitioners to contact 911 in an emergency. A call to 911 can result in a range of provider responses with varying education and training. Families may interact with county law enforcement, city police departments, state police, or school district police officers. An officer's response to a child's mental health crisis may vary depending on his or her level of education and experience in child mental health. Families reported several concerns with the officers: officers lectured their children, they threatened to lock the child up, or the officer blamed the child's behavior on poor parenting. Parents also expressed concerns about law enforcement responses such as: handcuffing children, tasing children, or pulling service revolvers on children. Additionally, there was a concern that contacting law enforcement resulted in charges that engaged their child in the juvenile justice system instead of the mental health system. Contacting law enforcement can result in charges of assault or destruction of property (Geddes, & Walker, 2003).

Additional Crisis Services

Additional crisis services include mobile crisis teams, crisis hotlines, mental health urgent care services, emergency respite, emergency department diversion, and care coordination and stabilization. Mobile crisis teams are trained mental health providers that come to the location of the crisis (i.e. home, school) to help during and after the crisis. Previous research suggests that when mobile crisis teams are available, families frequently utilize them while crisis hotlines may be less frequently utilized. Mental health urgent care services are walk-in clinics where children can be seen by a licensed mental health provider without an appointment for evaluation and referral. Emergency respite provides up to two weeks of care for a child when a family and/or child are overwhelmed and can take the form of residential or group home

settings. Emergency department diversion is a service where a licensed mental health clinician is available in the hospital emergency room to address the child's mental health crisis and determine hospital admittance. This service is intended to divert children from the hospital but often also results in expediting inpatient care. Care-coordination and stabilization is a long-term community support that helps a family both during and after a crisis in an attempt to avert the next crisis. Families report a desire for intensive community-based services in lieu of inpatient hospitalization (Geddes, & Walker, 2013).

School-Based Services

Schools are the primary source of services for children with mental health disorders on the continuum of mild to severe (Koppelman, 2004). One study found as many as 80% of children who received mental health services did so through a school-based program (Burns, et al., 1995). Schools are a major provider of services because federal legislation mandates they serve children with emotional disturbances. Despite this mandate, a narrow interpretation of special education criteria may lead only those who are severely impaired actually receiving services (Koppelman, 2004). An additional factor in schools becoming a primary provider of mental health services is linked to the current focus on academic achievement and school performance. Emotional well-being is connected to academic performance. Schools have received pressure to increase student performance; as a result, they have begun increasing services to children who did not qualify for special education services but are at-risk for diagnosis of mild to moderate disorders (Koppelman, 2004).



Children may receive mental health services in the public school setting through the Individuals with Disabilities Act (IDEA). IDEA is federal legislation that mandates the provision of services necessary for a child to engage in the educational system. These services may be limited based on school districts interpretation of the law (Bazelon, 2000). At a cost of 5.7 million dollars, IDEA served 11.5 % of students between 6 and 21 in the 2000-2001 school year while also serving 5% of the preschool population (Koppleman, 2004). Children can qualify for IDEA in 13 categories: learning disability, speech and language impairment, mental retardation, emotional disturbance, multiple disabilities, hearing impairment, orthopedic impairment, visual impairment, autism, deaf/blindness, traumatic brain injury, developmental delay, and other health impairments. Most children with mental health disorders receive services under specific learning disabilities, emotional disturbance, or other health impairment (Koppelman, 2004).

Children with serious emotional disturbances qualify for services through IDEA under the emotional disturbance category. For children to qualify, they must have a psychiatric diagnosis and their school performance must be impacted by one or a combination of: an inability to learn that is not explained by other health deficits, an inability to form and maintain relationships with peers and teachers, general depression, inappropriate feelings and behaviors, and physical symptoms or fears resulting from personal or school problems. Over 400,000 children in the US received services under the emotional disturbance category in the 2000-2001 school year (Koppelman, 2004).

When children qualify for IDEA under the emotional disturbance category, they are entitled to intensive classroom help. Students may receive therapy, intensive outpatient treatment, or residential treatment, but students may only receive the services that are necessary for them to learn. Schools are not required to provide medication. The courts have set a precedent for excluding family therapy and respite services under IDEA, services which families may need to effectively parent a child with a serious emotional disturbance (Koppelman, 2004).

Although 5% of children have a serious emotional disturbance and are in need of services under IDEA, in 2001, only 1% of children qualified for the emotional disturbance category of services (Koppelman, 2004). These children are often misidentified under the learning disability category (Redden, Forness, Ramey, Ramy, & Brezaussek, 2002). Children under the category of learning disability are less costly to treat than those receiving services under the emotional disturbance category (Chambers, Shkolnik, & Perez, 2003). Schools may also be reluctant to classify children under the emotional disturbance category to avoid stigma and may assume that the children are receiving services through other systems. Most children with a serious emotional disturbance have contact with multiple systems of care and receive services through special education (Seltzer, 2003). Children who are receiving services under the emotional disturbance classification routinely do not receive all the services they need (Koppelman, 2004; Mattison, 1999).

Because schools are the primary social environment for children, it has been advocated that school-based mental health services be expanded (President's New Freedom Commission on Mental Health, 2002). Forty-five states have on-campus health and mental health services. Sixty percent of campuses in those states provide mental health staff and 80% provide crisis intervention staff. Students primarily use school-based mental health centers to meet their needs (Strozer, Juszczak, Ammerman, 2010). Some states (for example New York and Connecticut) provide a separate mental health clinic on school grounds dedicated to children's mental health needs (Koppelman, 2004).

The Children's Services Program funded by the Substance Abuse and Mental Health Services Administration (SAMHSA) is the largest federal direct services program for children's mental health. The program provides community grants that allow communities to provide the treatment needed to keep children at home (including case management, respite, day treatment, and family counseling). The program services approximately 6,000 children a year.

Community Mental Health Services Block Grant (MHBG)

- ◆ Provides funds and technical assistance to provide comprehensive, community-based mental health services to adults and children with serious emotional disturbances
- ◆ Monitors progress of implementing a comprehensive, community-based mental health system

(SAMHSA, 2014)

The intersection of mental health and child welfare

Prevalence of Relinquishment

Although federal law requires states to make reasonable efforts to prevent removal and keep children with their families (Adoption and Safe Families Act, 1997), anecdotal evidence suggests that children enter foster care solely for the purpose of receiving mental health treatment. There are no reliable nationally representative statistics to document this phenomenon. One study that utilized a convenience sample of caregivers of children with mental health issues found that 23% of parents had been told they would have to relinquish custody of their children in order for their children to receive mental health services; 20% reported relinquishing their child, and 36% reported their child being placed in the juvenile justice system due to their unmet mental health needs (National Alliance for the Mentally Ill, 1999).

The U.S. General Accounting Office (GAO) reported that 12,700 children were relinquished nationwide in 2001 so that they could receive mental health services (U.S. General Accounting Office [GAO], 2003). These estimates are likely to be conservative. Some states do not track children who enter the system due to a mental health need. Additionally, the GAO report attempted to capture all states, but 32 states did not respond to requests for information including the 5 states with the highest population of children (GAO, 2003). Texas did not provide data on the number of children entering the child welfare system solely to obtain mental health services. The reason for lack of data on Texas was cited as “The practice of voluntary placement or relinquishment is either not legal in the state or the state generally does not allow parents to place their children in foster care voluntarily” (GAO, 2003).

Although a high proportion of children with mental health needs come from low-income families (New Freedom Commission on Mental Health, 2003), relinquishment affects families at all income levels (GAO, 2003). Middle class families may not have access to Medicaid benefits and their private insurance may not be adequate to cover the high cost of mental health care (Goodman, 2003). The cost of appropriate treatment, especially residential treatment, may be unattainable even for high income families, and families may be advised to relinquish their child to gain access to state Medicaid benefits (DeRigne, 2010). Once a child is placed in foster care, they qualify for Medicaid under Title IVB of the Social Security Act (Koppelman, 2004).

Factors Influencing Relinquishment

Several factors affect parental relinquishment. These include: lack of access to mental health services, gaps in coverage and coverage limitations, and challenges in accessing mental health services through public agencies (GAO, 2003).

The lack of services available to families in the community and the lack of adequate funding of mental health services through private insurance and Medicaid place families in a desperate situation. While parents may not be able to access services on their own, federal law requires

states to provide mental health services for children in state custody (42 USCA 671). Children in the custody of the state child welfare system have access to services that may not be available to children in the custody of their families (Pear, 2003).

Barriers to Accessing Services

Families are impacted by gaps in mental health coverage and limits to coverage. While some mental health services are not covered at all, others may be covered but have limitations on the duration or intensity of treatment. Often, intensive services in the community are not covered, causing more costly residential services to be necessary. Families face limited mental health resources in their home communities. The issues caused by gaps in coverage and scarcity of resources are compounded by a lack of coordination between agencies. Agencies vary in their eligibility requirements making coordinated care challenging. Furthermore, agency policies may be so complex that they are complicated even to those employed with the agency. This complexity can result in families receiving inaccurate information about services (U. S. General Accounting Office, 2003).

Legal considerations

Families who have a child with serious emotional disturbance (SED) who cannot get the care they need for the child in some cases reach a point where they cannot maintain the child in their home any longer. The child may become a danger to him or herself, to the family, or may require extensive inpatient services that the family simply cannot afford or access. In these situations, if the family determines it cannot care for the child in the family home and no other support services are available, the family may feel compelled to relinquish temporary (or more rarely, permanent) custody of the child to DFPS in order to secure mental health services for the child.

Because Texas' child welfare system does not have a "voluntary placement" option, currently children come into foster care if the following conditions are met:

- abuse or neglect has been confirmed, or DFPS has evidence that there is an immediate danger to the physical or safety of the child or the child has been a victim of neglect or sexual abuse,
- DFPS has made reasonable efforts to prevent removal, and
- a court has ruled that removal from the home is necessary for the child's welfare.

In most instances in which a family relinquishes custody to obtain mental health care, the parents' actions or omissions involving the child meet the statutory definitions of abuse or neglect, and DFPS makes a finding that the person abused or neglected the child which results in the caregiver's name being placed on the Texas child abuse registry. At the end of an investigation, DFPS sends the parent a letter informing them about the abuse or neglect finding against them, which includes information regarding their legal right to appeal the finding through an Administrative Review of Findings (ARIF; Texas Family Code Sec 261.309, Review of Department Investigations.). If the ARIF upholds the finding, the person is notified in writing that they can appeal the finding through the DFPS Office of Consumer Affairs. If

the finding is overturned in either review, DFPS takes the person's name off of the central registry.

The Department of Family and Protective Services (DFPS) maintains the state of Texas central registry in DFPS' automated case record system named the Information Management Protecting Adults and Children in Texas (IMPACT).

Inclusion on the registry can impact the caregiver's ability to work in certain DFPS programs, DFPS regulated child care or 24 hour care facilities, or in a very limited number of non-DFPS volunteer programs with children or vulnerable adults, if Texas law or rule requires a central registry check to be conducted on potential or current employees or volunteers for that type of program or facility. For DFPS-related decision making, inclusion on the registry does not automatically bar an individual from any employment or role with the agency, but a risk evaluation may need to be conducted to determine if the individual's past poses a current risk to children in the program or facility in which the individual wishes to work. It could also impact the caregiver's ability to foster or adopt children in the future from DFPS or independently, as individuals seeking to become approved foster or adoptive parents have to have a registry check conducted. Except as designated below, DFPS does not release central registry information to any potential employer outside of DFPS but rather provides the information to the person checked who then may decide whether or not to share it with the employer.

However, if a person in a DFPS case was determined to have abused or neglected children and to pose a substantial risk to the health and safety of children or adults outside the case that was investigated, DFPS may release the information to the employer after a hearing by the State Office of Administrative Hearings (SOAH) upholds the finding. If DFPS determines there is an immediate and substantial risk to the health or safety of children or adults, DFPS notifies the caregiver of the release of information and offers the person the right to a SOAH hearing. If the SOAH Administrative Law Judge (ALJ) overturns DFPS' abuse or neglect finding, DFPS notifies the person and the potential employer of the overturned findings. If the ALJ upholds DFPS' finding, the person is informed that their name will remain on the registry.

However, more could be done to ensure parents are made aware of their rights in the CPS system and the consequences of relinquishment so the caregivers can make an informed decision about pursuing relinquishment of the child to DFPS.

Best Practices for Meeting the Needs of Children with Serious Emotional Disturbances

The Surgeon General has recommended that a continuum of services be available to children and families including:

- Intensive psychosocial rehabilitation services
- Hospital and other 24 hour services
- Intensive community services
- Outpatient services
- Medication management
- Case management
- Family based services
- Integrated community networks of care

The provision of a range of services ensures that children with a serious emotional disturbance can receive the appropriate intensity of services in the least restrictive setting (U.S. Department of Health and Human Services, 1999; U.S. Public Health Services, 2001). Most families who have a child with a serious emotional disturbance will at some time face a mental health crisis. These crises may precipitate relinquishment. Additional services for supporting a family in crisis include: mental health urgent care, treatment providers creating a crisis plan with a family before a crisis occurs, training law enforcement to respond to a child's mental health crisis, the availability of 24/7 mobile crisis teams, and the provision of mental health training in schools (Maryland Coalition for Children's Mental Health, 2002). An examination of established and emerging best practice as well as family support programs implemented in other states follows. While states are implementing programs to assist families, evaluations of those efforts are forthcoming.

Increase Integrated Care

Best practices support states promoting integrated care. By integrating mental health and primary care, states can prevent duplication and gaps in services. Medicaid resources can be allocated to promote integrated care through community mental health centers (Texas System of Care, 2014).

Expand Medicaid

Only 25 states and the District of Columbia have implemented Medicaid waiver expansions to serve families who have children with serious emotional disturbance. Medicaid expansion provides more children with serious emotional disturbances with the levels of services needed. Texas has begun piloting expansion through the YES Waiver program described previously.



The Katie Beckett Option

States have the option to expand Medicaid benefits outside the traditional eligibility criteria of income and category. This Medicaid waiver option allows expanded funding of home-based and community-based mental health services for children. Under the Katie Beckett Option, states can provide comprehensive Medicaid benefits to children regardless of income as long as the children are living at home, without the benefits, and would require out of home care (Bazelon Center for Mental Health Law, 2002). In Texas, the YES waiver is currently being used in a similar fashion by providing youth community based care to keep them out of institutions.

Family-focused approaches to service delivery

Mental health systems should provide treatment that targets the family systems as a whole, not just the identified child. Caregivers should be involved in all components of planning and delivery of the child's treatment. Family involvement improves services (Brannan, Heflinger, & Foster, 2006).

Provide Strengths-based prevention and Intervention Strategies

It is important that children and youth have the opportunity to build on their strengths and prepare for adult competencies. In addition to addressing the youth's mental health needs, it is important to support their interests. By supporting youth in their interests (i.e. drama, art, music, sports) they are able to build on their strengths and build self-esteem. As youth progress toward adulthood they will also need help with job skills, budgeting, school, and housing (National Center for Children in Poverty, 2006).

Offer Services at Convenient Locations

Services should be available where families are already receiving other services. Needed services should be accessible in courts, school, and other non-mental health systems. This makes it easier for families to get needed services and also serves the function of reducing stigma (National Center for Children in Poverty, 2006).

Provide Caregiver Training and Support

It is critical to provide caregivers training and support on their rights, the rights of their children, and available services (National Center for Children in Poverty, 2006). Examples of programs that support this recommendation include family support groups. Several states and communities have examples of programs that support families in this way (see table 1 on next page).

Collect and analyze data

In order to fully understand the role of relinquishment for children and families managing serious emotional disturbances, it is important that states collect relinquishment data. A thorough understanding of the dynamics of families who relinquish and the systems they interact with is necessary in order to effectively support change (Maryland Coalition for Children's Mental Health, 2013).

Efforts in other states

States vary in both their mental health and child welfare policies. Table 1 lists efforts by various states. While there are practices in other states that are being used to prevent relinquishment, the outcomes of these efforts are largely unknown. Research has documented the issue of relinquishment, but evaluations have not documented best practices for preventing relinquishment.

Table 1. Family support programs by state*

State	Family Support Program	Program Goal
Florida	Families Latinas “Dejando Huellas”	Promote mental health of Spanish-speaking families and children through advocacy, service, and support.
Minnesota	Minnesota Association for Children’s Mental Health Parent-to-Parent Program	Build an information and support network of parents, children and youth with mental health problems.
Maryland	Baltimore Families First	Enable parents of children with developmental disabilities and mental health needs to access services.
New Jersey	The Family Support Organization of Burlington County	Provide one-on-one support, education, and advocacy for parents enrolled in intensive treatment in a care management organization as well as community outreach for other parents of children with behavioral, emotional or mental health problems.
Arizona	Latino Parent Support Group	Assist and support families and caregivers and help policymakers, agencies, and providers transform systems to ensure children and youth with emotional, behavioral, or mental health disorders succeed in school, live with their families, avoid delinquency, and become productive adults.

*Adapted from National Center for Children in Poverty (2006)

RESEARCH FINDINGS

Parents who have a child with serious emotional disturbance follow a predictable trajectory

Parents who have a child with serious emotional disturbance follow a predictable trajectory with predictable barriers despite the fact that their child's behaviors and needs are unique. This trajectory begins with a parent noticing a child's concerning behavior. In some cases, parents may notice concerning behaviors as early as toddlerhood. Other parents may not notice concerning behaviors until the child has experienced some sort of traumatic event. Regardless of when parents notice concerning behaviors, their first conversations about the behavior is generally with their pediatrician. Many parents report feeling that their child's behavior was their fault and they asked their pediatrician for advice on how to be a better parent for their child. As the child's behavior continued to escalate and cause concern, pediatricians are again consulted and the child may be prescribed medication.

Once a child enters school, behavioral concerns are pointed out to the parent by a teacher and/or school administration. Parents then begin a very difficult and complex process of qualifying their child for special education services so that they have the most appropriate learning environment. Parents often look to schools for guidance on where to find additional help for their child in the community.

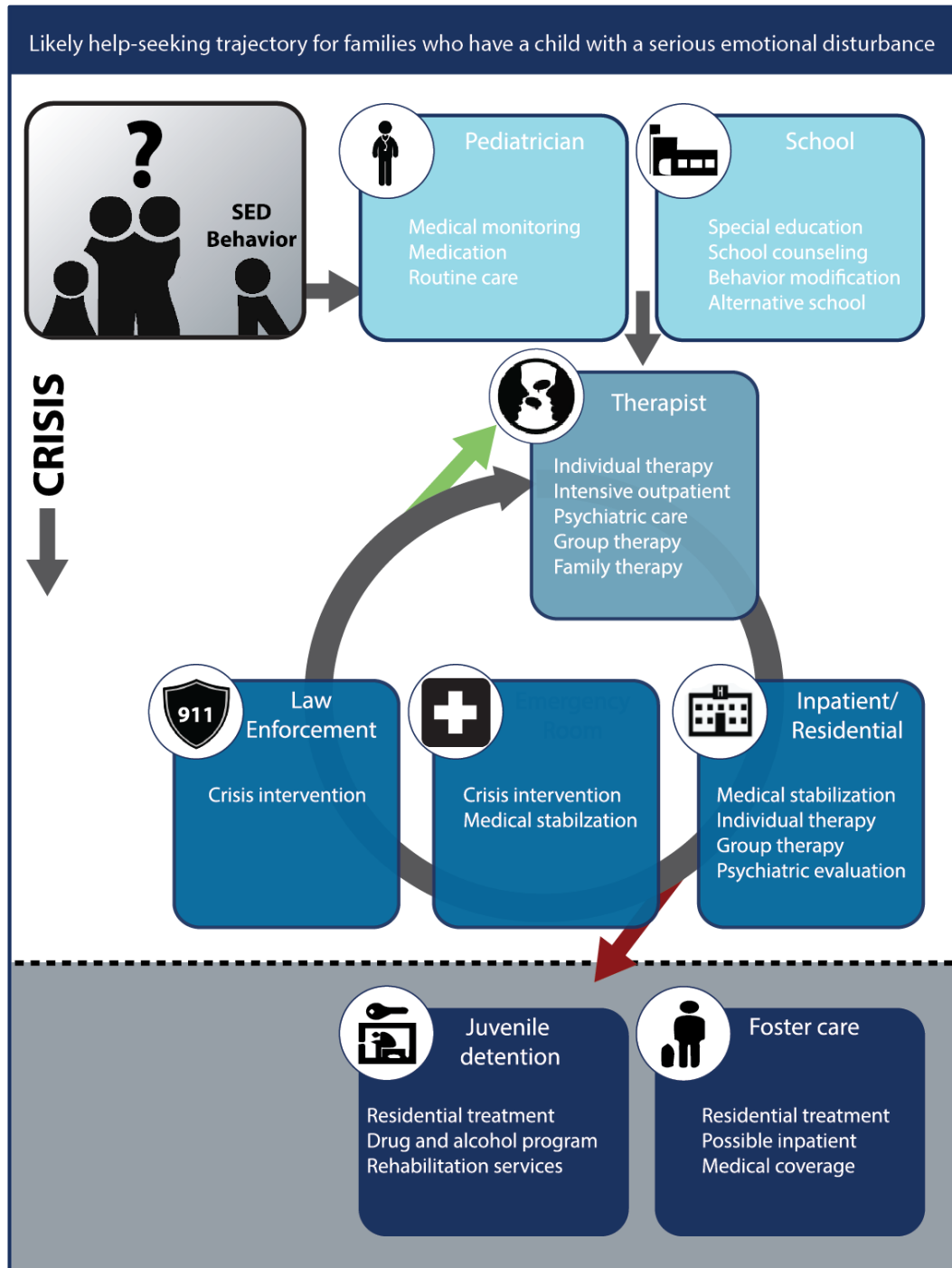
At this point, a pediatrician and/or school representative likely refers a family to a therapist and child psychiatrist. A therapist may provide counseling for the child and the family. The child psychiatrist will diagnose mental illnesses and provide medication management for the child. With proper medication management and therapy, a child may stabilize. In fact, many parents could recall a period in their child's life when there was a particular therapist who had developed a strong relationship with the child resulting in relative calm for the child and family.

If a therapeutic relationship was not strong or the child was triggered by an event, the family often entered into a cycle of seeking emergency help. During violent episodes or episodes where self-harm is imminent, families call 9-1-1. Law enforcement intervenes to protect family members from the child with serious emotional disturbance or to protect the child from hurting him or herself. First responders may transport the child to an emergency room for psychiatric treatment or arrest the child. Family members may also seek emergency assistance by taking the child directly to an emergency room for psychiatric treatment. Once at an emergency room, which are generally not equipped for child psychiatric emergencies, hospital staff work to find inpatient psychiatric treatment for the child. In some cases, finding inpatient psychiatric care may take days. If a family needs inpatient psychiatric treatment, they can contact facilities themselves, but often cannot find an open bed during a crisis. Once in an inpatient facility, children are provided medication management and hopefully, therapy. However, services at psychiatric facilities vary greatly and families feel that they are not well-regulated. After leaving an inpatient facility, parents sometimes describe a brief "honeymoon" period when their child is able to re-integrate back into their family and community-based therapy. Unfortunately, the cycle of law enforcement, emergency rooms, and inpatient facilities often becomes a norm for families. In this study, many parents could not even quantify the number of times they had been through the cycle described here.

After moving through the emergency cycle multiple times, families are emotionally and financially exhausted. About ¼ of families considered letting their child enter the foster care system. Other families face the reality of their child being incarcerated. In this study, some parents interviewed felt that incarceration was the safest place for their child. When families reach a point of considering foster care or juvenile detention, they are faced with a no-win situation: they can let

their child think she was abandoned by being placed in foster care or they can continue to call law enforcement and have their child arrested. Either way, a bond is broken between the parent and child.

Figure 1. Help seeking trajectory



Services exist that can help families

Both parents and advocates report benefits from services that already exist. For example, pediatricians are able to provide parents with guidance and referrals to child behavior specialists. In a best case scenario, a pediatrician is able to help parents understand that their child's behavior is not the result of poor parenting.









Schools can also help families, but that help is largely dependent on the resources in the school district. Schools must provide services to students with disabilities. However, those services are largely focused on academics. Schools may provide academic testing and psychological testing. After qualifying for services, some schools are able to offer learning environment modifications such as a specialized classroom. One parent reported that her child was assigned an educational aide who accompanied him throughout the day.

Community-based mental health services may be beneficial to parents and children. In some cases, children receive specialized music or art therapy that can be particularly useful. An important part of the child's services must include the family. Family therapy, respite care for the family, and support groups are all reported to be incredibly helpful to parents. For those children involved in wraparound services, community-based mental health focuses on the holistic needs of the child and family. These services are reported to be incredibly useful to families.

Once families enter the cycle of needing emergency help, there are some benefits to these services. Law enforcement may help protect the child and family during a time of crisis. One mother in this study reported developing a very positive relationship with the law enforcement in her community to the point that they helped connect her with additional services. When law enforcement was well-trained in mental health crisis management, they were able to assist in stabilizing a situation. Emergency rooms are used in crisis to provide immediate help to a child who may harm him or herself. One of the benefits of emergency room services is keeping a child safe while an inpatient bed is located. Inpatient services vary widely but may benefit the child and family by providing intense services and medication to stabilize the child.

Foster care and juvenile justice, while last resorts for families, do have benefits for a family that has cycled through crisis situations enough times. Often, families are financially and emotionally exhausted after dealing with multiple crises. They reach a point where foster care may become a potential solution because they know that the state will have to cover mental healthcare that they can no longer afford. For parents who fear their child might hurt a sibling, foster care and/or juvenile justice may be the only safe living options available.

Table 2. Benefits of different services

<p>School</p> 	<p>Often the first time someone other than family identifies concerning behavior Academic testing, limited psychological testing Alternative classroom settings Behavior Intervention Plan</p>
<p>Pediatrician</p> 	<p>Psychotropic medication Support and guidance Referrals to child psychiatrist, child behavioral specialists</p>
<p>Therapist</p> 	<p>Individual therapy including art therapy, music therapy, animal assisted therapy Family therapy Limited case management</p>
<p>Law Enforcement</p> 	<p>Crisis de-escalation Protection of family, siblings during violent episode Assistance in transporting to emergency room</p>
<p>ER</p> 	<p>Crisis management for suicide attempt or other self-harming behavior Entry point into inpatient psychiatric hospital Medication Stabilization</p>
<p>Inpatient</p> 	<p>Individual therapy Family therapy Crisis de-escalation Mental health treatment Prevention from harming self and others</p>
<p>Juvenile Justice</p> 	<p>24 hour supervision Crisis de-escalation Some mental health treatment</p>
<p>Foster Care</p> 	<p>24 hour supervision Mental health treatment Crisis de-escalation</p>

Serious emotional disturbance costs families, taxpayers

Within the current service structure, managing a child with serious emotional disturbance is costly for both parents and taxpayers. For parents and families, the emotional cost grows over time without appropriate services. Emotional cost is tied to the financial constraints they face. Table 3 details the costs to families and taxpayers.

For many families the financial cost extends beyond direct costs for services. Many parents report losing a job due to missed work while other families choose to survive off of one income so that a parent can be home to manage their child's behavior. Work is often difficult to navigate when parents have to attend meetings at schools, take their children to doctors and therapy appointments, handle crises, and spend time navigating very complex insurance policies. Additionally, the direct costs are substantial. Families reported paying \$400 a month for medication co-pays alone. One family paid an \$8,000 co-pay for just one inpatient stay. Families may also incur court fines and attorney fees if their child becomes involved in the juvenile justice system. For youth who enter foster care, parents are placed on a child abuse registry which may impact their ability to work with children in professional settings. For families who contact law enforcement, additional expenses may occur through court costs and attorney fees as their child becomes involved in the criminal justice system.

The emotional costs impact an entire family. Parents report feeling blame and stigma from people who believe their child's behaviors stem from bad parenting. Many parents internalize these ideas and blame themselves as well. Their relationships with other adults suffer because they cannot "take a break" from parenting. Siblings in the household also feel strain. They often cannot have their friends over for fear of the sibling's behavior. A child's behavior may escalate to the point where siblings are physically harmed and traumatized by serious emotional disturbance behavior (Kilmer, Cook, Taylor, Kane & Clark, 2008). Parents also report that they are unable to do normal family activities such as outings and vacations because of their child with serious emotional disturbance.

In addition to the financial and emotional cost to families, there is a clear cost to taxpayers for providing services to a child with serious emotional disturbance. In some cases, the cost estimates are very difficult to extrapolate. For instance, every school district differs in terms of services it provides. However, it is estimated that it costs \$21,258 annually for each special education student. Since serious emotional disturbance youth are frequently in special education, it is likely that the expense for children with serious emotional disturbance is around this estimate (TTARA, 2012).

If a child is receiving Medicaid, taxpayers cover the costs of services. For pediatric visits, Texas currently reimburses \$36 per visit not including lab work, x-rays, and medications (Texas Medical Association, 2014). Counseling sessions are reimbursed at \$100.08 (Texas Department of State Health Services, 2014b). Emergency room costs are difficult to tease apart. However, it is estimated that the average emergency room visit may cost \$1233 (Caldwell et al., 2013). Medicaid would only cover a portion of that cost leaving the remaining funds to be covered by counties and local hospital districts. The cost of inpatient services will vary widely depending on the facility. However, to estimate the cost, the average inpatient stay at the Waco Center for Youth, a state facility, is \$396 a day or \$75,240 for the average 190 day stay.

Public funds are also used to pay for law enforcement. There is a cost to the general public as law enforcement resources are diverted from other pressing issues. However, quantifying a cost per law enforcement call is not possible.

Finally, both juvenile justice placements and foster care cost taxpayers. DFPS estimates that 107 children in FY2012 and FY2013 entered the foster care system for the sole purpose of obtaining mental health treatment. A foster care placement for a child with serious emotional disturbance will cost the state \$260.17 a day. Assuming a child stays in care for one year, the cost for caring for that child is \$91,580 for the entire year. Appendix G details a more extensive cost analysis of foster

care placements. For juvenile justice facilities, the cost of incarceration and probation vary widely by county, but it is estimated that it costs \$366 per day to incarcerate a youth.

There are multiple, complex barriers to receiving services

While services may exist in communities, there are multiple barriers to receiving services that leave children and their families feeling hopeless. As noted above, families and advocates do report positive experiences with various services. However, access to quality services is inconsistent and parents spend a great deal of time learning how to navigate systems in order to get their child help. Services are often costly, unavailable or not useful. Table 5 details the challenges of receiving services.

Interestingly, the less costly options for families tend to be the least helpful. For instance, families do not pay for services received through public schools. However, most families find school services to be incredibly difficult. The special education process is complex and can take entire year to qualify for services. Thus, parents spend a great deal of time working with school administrators to manage behavior and move through the qualification process for special education. In some cases, parents may have to battle to get their child appropriate testing. In other cases, school administrators may use suspension and other disciplinary actions to push the child into alternative school settings.

Law enforcement is another option that is not costly to the family, as public funds cover the cost. However, most law enforcement officers have minimal training on mental health issues. Some departments have mental health teams, but these teams are still rare in most areas. Without appropriate mental health training, officers may actually escalate crisis situations for families. In some cases, they may arrest a youth when parents simply needed help to de-escalate a crisis.

Emergency room services are widely available as most communities have emergency medical care, yet they are not useful for families. Indeed, emergency rooms were not designed to treat acute mental health crises. Families who must use emergency rooms find that staff are judgmental and generally lack knowledge about mental health. Oftentimes, child protective services workers are called, but can provide families little help beyond what they have already tried. Emergency rooms are incentivized to discharge children and attempt to find inpatient hospital beds quickly, even if the particular inpatient facility is not the right fit for the child.

Inpatient facilities are inaccessible and unaffordable to families. Wait times to get into a facility can be months. Insurance pre-approval is a difficult maze for parents. Furthermore, a pressing issue parents and advocates have with inpatient facilities is the standard of care their children receive. Parents report their children being forcibly medicated and not engaged in activities or therapy. In many cases, children have been at multiple facilities in an attempt to find a “good one.” Once insurance runs out on the inpatient stay, children are often discharged with only a week’s worth of medication and a referral to a psychiatrist who will not be able to see the child within a week.

Community and school-based mental health appear to be the most accessible services for families. Even with co-pays, counselors in the community will cost families less than inpatient treatment. In particular, families report wraparound services as being very useful as they consider the needs of the entire family. Most families could speak to one or two therapies that worked with their child, but for whatever reason, became unavailable to the family.

Table 3. Cost to families and taxpayers














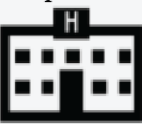


	Cost to family	Cost to society
 <p>School</p>	<p>Lost wages for parent to attend special education/disciplinary action meetings</p> <p>Lost wages if child gets suspended</p> <p>Possible expenses related to obtaining additional psychological testing</p>	<p>Special education services per pupil is \$21,258</p> <p>(Based on school finance weights (TTARA, 2012))</p>
 <p>Pediatrician</p>	<p>Lost wages for parents to attend appointments</p> <p>Co-pays/private pay for visits, testing, medications, and follow-up services</p>	<p>Each doctor visit costs Medicaid \$36, not including any labs, x-rays and medication costs</p> <p>(Based on estimate from the Texas Medical Association)</p>
 <p>Therapist</p>	<p>Lost wages for parents to attend appointments (therapy/psychiatrist)</p> <p>Co-pays/and or private pay for visits, medications</p>	<p>A one hour counseling session is reimbursed at \$100.08.</p> <p>(Based on cost reimbursement rates for YES waiver)</p>
 <p>Law Enforcement</p>	<p>Emotional cost to child and family</p> <p>Possible court fines, attorney fees</p> <p>Stigma</p>	<p>Time of officers diverted from community policing</p>
 <p>ER</p>	<p>Expensive co-pays, ambulance fees, medication costs</p> <p>Lost wages to stay with child in hospital</p> <p>Emotional cost to families</p>	<p>The average emergency room visit costs \$1233 (Caldwell et al., 2013)</p> <p>Medicaid only pays a portion of this cost leaving a remaining cost for local taxpayer and hospitals to cover</p>
 <p>Inpatient</p>	<p>Expensive co-pays or private pay</p> <p>Travel costs and lost wages for families to visit, navigate health insurance</p> <p>Emotional cost to child and family</p>	<p>Average cost of inpatient care is \$75,240 per visit</p> <p>Based on cost for Waco Center for Youth, (HHSC, 2012)</p>
 <p>Juvenile Justice</p>	<p>Emotional cost to child and family</p> <p>Possible court fines, attorney fees</p> <p>Criminal history may impact future job</p> <p>Lost wages for hearings, meetings</p>	<p>The daily average cost to the state of incarcerating youth is \$366.88</p> <p>Based on Criminal Justice Uniform Cost Report, Years 2011-2012); Note: Local costs for youth incarceration will vary by county and are not included in this estimate</p>
 <p>Foster Care</p>	<p>Emotional costs to child and family</p> <p>Job impacted by child abuse registry</p>	<p>The daily average cost to the state to provide residential treatment to foster youth with intense needs is \$260.17</p>

Table 4. Barriers to getting services/ Common problems with services

<p>School</p> 	<p>Schools and school district vary in the services they provide</p> <p>Schools provide testing in relation to academics; parents may have to find other sources to get psychological testing</p> <p>There is usually a delay, sometimes a year or more, in getting a student into specialized classes</p>
<p>Pediatrician</p> 	<p>Pediatricians are not specialized in children’s mental health and appropriate psychotropic medications</p> <p>Pediatricians often cannot get child psychiatrists to participate in consultations to provide the best care for children and families</p>
<p>Therapist</p> 	<p>Lack of child psychiatrists</p> <p>Therapist accessibility is largely dependent on insurance coverage</p> <p>Much therapy is child focused instead of including the entire family</p> <p>Counseling interns are often used in schools which creates instability for children</p>
<p>Law Enforcement</p> 	<p>Most officers are not well trained to handle child mental health crisis</p> <p>Judgment of parents by officers</p> <p>Instills fear in children</p>
<p>ER</p> 	<p>Can only keep child based on insurance approval</p> <p>Often do not understand children’s mental health and blame, judge parents</p> <p>Refer parents to same inpatient facilities and resources that have already not worked</p>
<p>Inpatient</p> 	<p>“Good” facilities are costly; Insurance often refuses recommended length of stay</p> <p>Facilities release youth with only a week’s worth of medication and referral to a psychiatrist who will not be able to see the child within a week</p> <p>Lack of family inclusion in therapy/Lack of re-integration services</p> <p>Lack of monitoring of conditions</p>
<p>Juvenile Justice</p> 	<p>Restrictive environment</p> <p>Child has criminal justice history</p> <p>Deterioration of trust between parent and child</p> <p>Child’s Medicaid is terminated after 30 days, reinstatement process is lengthy</p>
<p>Foster Care</p> 	<p>Deterioration of trust between parent and child</p> <p>Parents are placed on child abuse registry</p> <p>Additional trauma caused by placement with another family</p>

There is a cost to not serving these children

While the costs of serious emotional disturbance are high to families and taxpayers, the costs of not stabilizing children is greater. Children who are not provided care that stabilizes them and provides assistance for their families will have their education disrupted and risk not graduating from high school. Thus, they have limited earning potential as adults. Children are socially isolated from their family and peers as their school and family life is disrupted. Children with serious emotional disturbance are at a high risk of entry into the juvenile or criminal justice systems and/or foster care. Finally, children with serious emotional disturbance are at a high risk of premature death, primarily due to their suicide risk. Several parents in this study shared that they saw little hope in their children's future and predicted that by 18 years old, their child would be dead or in jail.

For families, lack of treatment and stabilization leads to dire financial and emotional consequences. Families reported losing jobs, homes, cars and relationships due to their child's illness. An even greater consequence for families appears to be the loss of a relationship and trust with their child.

For society, not treating serious emotional disturbance results in the loss of economic productivity of the child and the loss of a contributing member of society. The financial cost to taxpayers increases as untreated behavior becomes more and more serious requiring expensive options such as juvenile justice and foster care placement. Finally, there is some potential for violence to others. Although the vast majority of individuals with mental illness never commit violent acts against others, there is some potential that an individual with serious emotional disturbance would hurt others.

Figure 2. Cost of not getting services



CONCLUSIONS

The findings from this report are presented to DFPS and DSHS along with these conclusions to facilitate the development of recommendations from the agencies regarding alternatives to prevent relinquishment.

This is a public health issue, not an issue for child protection.

Children’s mental health is a public health issue. The focus of preventing children with SED from entering the foster care system should be on providing necessary services so that families do not reach the point where relinquishment is an option. Best practices suggest the importance of treating mental health like other public health issues. It is well documented that good mental health is part of good overall health.

The mission of the Texas Department of Family and Protective Services is “to protect children, the elderly, and people with disabilities from abuse, neglect, and exploitation by involving clients, families, and communities.” Consistent with its mission, DFPS is not equipped to adequately provide mental health services. The training, experience, and structure and resources of the department are targeted toward protecting vulnerable Texans from abuse and neglect; not the treatment of mental health.

Stakeholders documented the historical tendencies to shift the responsibility for children with SED between state departments. A coordinated, well-funded effort is needed to allow collaboration between the Department of State Health Services and the Department of Family and Protective Services. Such a collaboration should have dedicated full time staff at each agency responsible for coordinating wraparound services for youth with SED.

Families need access to the services that are most useful to them.

Families generally prefer wraparound services, supportive case management, quality psychiatric services and in-home care. At this time, few of these services are affordable and accessible to families. Even when families have the financial resources to access services for their children they are likely to experience long waits, particularly for child psychiatrists. Delays in evaluation, treatment, and intervention result in a progression of the mental health condition, thus creating a cycle of insufficient available treatment. By the time a child is able to access a service they are already in need of the next level of service.

The shortage of child psychiatrists is particularly concerning. The information gathered in this study suggests that this shortage is critical; children wait as long as 2 years for an assessment and families must travel large distances to access care. There are only 182 child psychiatrists in Texas which means there are not enough to cover all the 254 counties in Texas (Texas Statewide Health Coordinating Council, n.d.). This shortage has a ripple effect on other services. With a shortage of child psychiatrists, primary care providers are more likely to be treating complex mental health conditions. These providers may not be knowledgeable about psychiatric medications. Further, shortages make it less likely that these providers will be able to consult with a child psychiatrist. This shortage increases the likelihood that a child will not receive appropriate care which can result in an escalation of the mental health condition. An escalation in symptoms means that children are more likely to require emergency and inpatient services which are both costly and limited.

Stakeholders and families emphasized the need for inpatient, intensive outpatient, and residential treatment centers. A lack of adequate and accessible resources in these areas leads to relinquishment. These services are limited and may not be

covered by insurance, or may be covered minimally, making this type of service completely out of reach for families. Families seek inpatient treatment when the child's behavior has escalated to the point that it is no longer safe for them to care for them in the home. If the family does not have the financial resources to access this type of care then they are left with the decision of endangering their child or others or relinquishment. Further, intensive outpatient services can be an important bridge between outpatient counseling and expensive inpatient options. Although weekly outpatient treatment was ranked as one of the most accessible services to families, it is not always adequate for children with a serious emotional disturbance. Intensive outpatient services allow the child to remain in their home but get intensive services that may stabilize them to avoid inpatient hospitalization. These services can include things like daily groups, daily therapy sessions, and day programs. The services are more frequent, more intensive and, although they can be expensive, not nearly as expensive as inpatient treatment. Unfortunately, these services are often not covered by insurance or are covered in such a limited capacity that they are out of reach for families.

Finally, an important component of care is in-home care. In-home care allows families to have much needed assistance in their homes. Families talked about the constant caregiving needed for a child with a serious emotional disturbance. Some families shared not being able to attend training that would have helped them gain skills for working with their child because they had no one to care for their child. For some families, the lack of an in-home caregiver resulted in parents having to leave jobs because there was no one to provide care to their child after school and their child's behavior was too intense for participation in regular after school activities. In-home care helps avoid caregiver fatigue and ultimately supports children being able to stay in the home.

Pediatricians need assistance in making referrals and consulting with psychiatrists.

The extreme shortage of child psychiatrists burdens primary care physicians. Because parents are not able to access the services of a child psychiatrist, they must rely on the child's pediatrician to prescribe and manage psychiatric medication. Pediatricians may not have the depth of training and experience specifically related to child mental health needed to monitor a child with a serious emotional disturbance. In order to adequately provide services to children with serious emotional disturbances, it is critical that pediatricians have support in making referrals when needed and have access to child psychiatrists for consultation when working with children. At this time, child psychiatrists and pediatricians are not able to bill Medicaid and private insurances for completing consultations with each other.

Emergency services are needed by families to keep their children at home.

Initial evaluation of the YES waiver program shows that it is effective. Further, stakeholders that participated in this study report the YES waiver program to be effective. A primary concern for stakeholders is the limited reach of this program. The YES program needs to be available to all children who need the services. Participation in the YES Waiver program not only resulted in improved outcomes for children but resulted in a decrease in utilization of expensive mental health services such as inpatient hospitalization (Texas Institute for Excellence in Mental Health, 2012).

In addition to expanding the YES waiver program, additional Department of State Health Services (DSHS) beds are needed. Children who are at risk of relinquishment have reached a level of care requiring inpatient and residential treatment services because they are at risk of harming themselves or others. Expanding the number of beds available to children enables children to receive necessary services while still remaining in the custody of their parents. Remaining with their families means that children do not have to experience the cumulative trauma of being removed from their home environment and a fractured parental relationship. When children are relinquished in an effort to get services necessary to preserve their safety or the safety of others, their mental health condition may escalate and be exacerbated by feeling of abandonment and rejection.

Serious emotional disturbance is a disability.

Parents of a child with an emotional disturbance face overwhelming stigma from their peers, professionals and their families. Often they are viewed as parents in need of parenting help rather than parents who are caring for a child with special needs. Parents often internalize this stigma to the point where they blame themselves for their child's behavior. At times, they may be reluctant to seek help because they fear being judged as bad parents. In contrast, parents who have a child with a physical or intellectual or developmental disability have multiple options for care open to them. Both resources are available to assist the family with in-home caretaking, respite care and general support.

More information and options are needed regarding child abuse registry.

Families who have a child with serious emotional disturbance may not be able to access further help without either having to refuse to accept parental responsibility for their child or abandoning their child. In either case, this relinquishment results in placement on the child abuse registry which has the potential to impact their professional career. More information needs to be made publicly available so that parents are aware of what the registry is and what their rights are regarding the registry. The Department needs to create a mechanism for removing a parents name from the registry in cases where a parent is seeking mental health treatment for a child. One strategy for accomplishing this task might be to allow judges to recommend removal if parental rights are terminated because judges are most familiar with a case.

REFERENCES

- Aber, J. L., Jones, S., & Cohen, J. (2000). The Impact of poverty on the mental health and development of very young children. In C. H. Zeanah, Jr., *Handbook of infant mental health* (2nd ed., pp. 113-128). New York, NY: Guilford Press.
- Adoption and Safe Family Act of 1997, Pub.L.No. 105-89, 111 Stat. 2115 (1997).
- Annapolis Coalition on Behavioral Health Workforce. (2007). *Action plan on behavioral health workforce development*. Washington, DC: Substance Abuse and Mental Health Services Administration, Publication No. 280-02-0302.
- Bazon Center for Mental Health Law. (2000). Keeping families together: Preventing custody relinquishment for access to children's mental health services. Washington, DC: Bazon Center for Mental Health Law.
- Bazon Center for Mental Health Law. (2003). Making the right choices: Reforming Medicaid to improve outcomes for people who need mental health care. Washington, DC: Bazon Center for Mental Health Law.
- Bilchik, S. & Nash, M. (2008). Child welfare and juvenile justice: Two sides of the same coin. *Juvenile and Family Justice Today*, Fall 2008, 1-20.
- Birkel, R. C. (2003, July). *Nowhere to turn: Must parents relinquish custody in order to secure mental health service for their children?* Retrieved from National Alliance on Mental Health (NAMI): http://nami.org/Content/ContentGroups/Policy/Testimony1/Statement_on_Child_Custody_Relinquishment_from_NAMI_Executive_Director_Rick_Birkel.htm
- Boesky, L.M. (2002). *Juvenile Offenders with Mental Health Disorders: Who Are They and What Do We Do With Them?* Lanham, MD: American Correctional Association.
- Brannan, A. M., Heflinger, C. A., & Foster, E. M. (2003). The role of caregiver strain and other family variables in determining children's use of mental health services. *Journal of Emotional and Behavioral Disorders*, 11(2), 77-91. doi:10.1177/106342660301100202
- Brannan, A. M., Athay, M. & Vides de Andrade, R. (2012). Measurement quality of the caregiver strain questionnaire-short form 7 (CGSQ-SF7). *Administration Policy Mental Health*, 39, 51-59. doi:10.1007/s10488-012-0412-1
- Brindis, C.D., Morreale, M.C. & English, A. (2003). The unique health care needs of adolescents. *Future Child*, 13, 117-135.
- Buckner, J. C., Beardslee, W. R., & Bassuk, E. L. (2004). Exposure to violence and low-income children's mental health: Direct, moderated, and mediated relations. *American Journal of Orthopsychiatry*, 74(4), 413-423.
- Burns, B.J., Costello, E.J., Angold, A., Tweed, D., Stangl, D., Farmer, E.M. & Erkanli, A. (1995). Children's mental health service use across service sectors. *Health Affairs*, 14(3), 147-159.
- Busch, S. H., & Barry, C. L. (2007). Mental health disorders in childhood: Assessing the burden on families. *Health affairs*, 26(4), 1088-1095.
- Caldwell, N., Srebotnjak, T., Wang, T. & Hsia, R. (2013). How much will I get charged for this?: Patient charges for top ten diagnoses in emergency department. *PLOS One*. Retrieved from: <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0055491>
- Campbell SB, Shaw DS, Gilliom M. Early externalizing behavior problems: Toddlers and preschoolers at risk for later maladjustment. *Development and Psychopathology*. 2000;12:467-488.
- Center for Disease Control and Prevention (CDC). (2014). *WISQARS injury morality Reports, 1999-2007*. Retrieved from CDC: http://www.webappa.cdc.gov/sasweb/ncipc/mortrate10_st.html
- U.S. Census Bureau. (2010). *Statistical Abstract of the United States*.
- Chambers, J.G., Shkolnik, J., & Perez, M. (2003). Total expenditures for students with disabilities, 1999-2000: Spending variation by disability. Palo Alto, CA: American Institutes for Research
- Children's Defense Fund. (2014). *Number and percentage of uninsured children in each state*. Retrieved from: <http://www.childrensdefense.org/policy-priorities/childrens-health/uninsured-children/uninsured-children-state.html>
- Children's Hospital Association of Texas. (2006, May). *Children's mental health in Texas: A state of the state report*. Retrieved from: <http://www.childhealthtx.org/Children's%20Mental%20Health%20in%20Texas-State%20of%20a%20State%20Report.pdf>
- Cocozza, J. & Skowyra, K. (2000). *Youth with mental health disorders: Issues and emerging responses*. Washington, DC: Office of Juvenile Justice and Delinquency Prevention.

- DeRigne, L. (2010). What are the parent-reported reasons for unmet mental health needs in children? *Health & Social Work, 35*(1), 7-15.
- Domalanta, D.D., Risser, W.L., Roberts, R.E. & Risser, J.M. (2003). Prevalence of depression and other psychiatric disorders among incarcerated youths. *Journal of the American Academy of Child and Adolescent Psychiatry, 42*(4), 477-484.
- Eisenberg, N., Cumberland, A., Spinrad, T.L., Fabes, R.A., Shepard, S.A., Reiser, M., Murphy, B.C., Losoya, S.H. & Guthrie, I.K. (2001). The relations of regulation and emotionality to children's externalizing and internalizing problem behavior. *Child Development, 72*(4), 1112-34.
- Feinberg, E., Swartz, A., Zaslavsky, A., Gardner, J., & Walker, D. K. (2002). Family income and the impact of a children's health insurance program on reported need for health services and unmet health need. *Pediatrics, 109*(2), 29-39.
- Fox, H.B., McManus, M.A. & Reichman, M.B. (2003). Private health insurance for adolescents: Is it adequate? *Journal of Adolescent Health, 32*(6), 12-24.
- Fox, M. H., Moore, J., Davis, R., & Heintzelman, R. (2003). Changes in reported health status and unmet need for children enrolling in Kansas children's health insurance program. *American Journal of Public Health, 93*, 579-589.
- Fraser, M. E. (2006). Child mental health policy: Promise without fulfillment? In J. M. Jenson, & M. W. Fraser, *Social policy for children and families: A risk and resilience perspective* (pp. 93-130). Thousand Oaks, CA: Sage Publications.
- Geddes, A. M., & Walker, J. A. (2013). Listening and learning from families: Crisis services and the experience of families caring for children and youth with mental health needs. Columbia: Maryland Coalition of Families for Children's Mental Health.
- Gershoff, E. T., Aber, J. L., Raver, C. C., & Lennon, M. C. (2007). Income is not enough: Incorporating material hardship into models of income associations with parenting and child development. *Child Development, 78*(1), 70-95.
- Giliberti, M., & Schulzinger, R. (2000). *Relinquishing custody: The tragic result of failure to meet children's mental health needs*. Washington D.C.: Bazelon Center for Mental Health Law.
- Ginsburg, C. & Demeranville, H. (2001) Sticks and stones, the jailing of mentally ill kids. In Ayers, W., Dohn, B. & Ayers, R. (eds.), *Zero Tolerance: Resisting the drive for punishment in our schools: A handbook for parents, students, educators, and citizens*. New York: New Press
- Goodman, G. (2003). Accessing mental health care for children: Relinquishing custody to save the child. *Albany Law Review, 67*, 301-329.
- Hazen AL, Hough RL, Landsverk JA, & Wood PA (2004). Use of mental health services by youths in public sectors of care. *Mental Health Services Research, 6*(4), 213-226.
- Hoagwood, K. E., Green, E., Kelleher, K., Schoenwald, S., Rolls-Reutz, J., Landsverk, J., . . . Mayberg, S. (2008). Family advocacy, support and education in children's mental health: Results of a national survey. *Administration Policy Mental Health, 35*, 73-83. doi:10.1007/s10488-007-0149-4
- Hogg Foundation for Mental Health. (2012). *2012-2013 Mental Health Policy Priorities*. Hogg Foundation for Mental Health. http://www.hogg.utexas.edu/uploads/documents/PolicyPriorities_distr_document_October2012.pdf
- Howell, E. M. (2004). *Access to children's mental health services under Medicaid and SCHIP*. Washington, DC: Urban Institute. Retrieved from <http://www.urban.org>
- Institute of Medicine (2002, July 17). *Reducing suicide: A national imperative*. Retrieved from: <http://www.iom.edu/Reports/2002/Reducing-Suicide-A-National-Imperative.aspx>
- Kaiser Family Foundatiion. (2007). *Children's coverage and SCHIP reauthorization*. Retrieved from http://www.kaiseredu.org/topics_imasp?id=704&imID=18parentID=65
- Kappahn, C., Morreale, M., Rickert, V. I., & Walker, L. (2006). Financing mental health services for adolescents: A background paper. *Journal of Adolescent Health, 39*, 318-327.
- Kataoka, S. H., Zhang, L., & Wells, K. B. (2002). Unmet needs for mental health care among U.S. children: Variation by ethnicity and insurance status. *American Journal of Psychiatry, 159*(9), 1548-1555. doi:10.1176/appi.ajp.159.9.1548
- Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005). Lifetime prevalence and age-of-onset distribution of DSM-IV disorders in the National Comorbidity Survey Replication. *Archives General Psychiatry, 62*(6), 593-602.
- Kilmer, R.P., Cook, J.R., Taylor, C., Kane, S.F. & Clark, L.Y. (2010). Siblings of children with severe emotional disturbances: Risks, resources and adaptation. *American Journal of Orthopsychiatry, 78*(1), 1-10.

- Knitzer, J., & Cohen, E. (2007). Promoting resilience in young children and their families at high risk: The challenge for early mental health. In D. F. Perry, R. K. Kaufman, & J. Knitzer, *Social and emotional health in early childhood: Building bridges between services and systems* (pp. 335-359). Baltimore, MD: Paul H. Brookes Publishing Co.
- Koppelman, J. (2004). Children with mental disorders: Making sense of their needs and the systems that help them. *National Health and Policy Forum*, 799, 1-24.
- Jianghong, L. (2004). Childhood externalizing behavior: Theory and implications. *Journal of Child and Adolescent Psychiatric Nursing*, 17(3): 93-103.
- Maryland Coalition of Families for Children's Mental Health. (2002). *Relinquishing Custody: An Act of Desperation*. Columbia, MD.
- Mattison, R.E. (1999). Use of psychotropic medications in special education students with serious emotional disturbance. *Journal of Child and Adolescent Psychopharmacology*, 9(3), 149-155.
- Medicaid and CHIP Payment and Access Commission. (2012, March). Report to the Congress on Medicaid and CHIP. Retrieved from: <http://www.modernhealthcare.com/Assets/pdf/CH78650315.PDF>
- Mental Health Parity and Addiction Equity Act of 2008, Pub. L. No. 110-343 (2008).
- McLearn, K. T., Knitzer, J., & Carter, A. S. (2007). Mental Health: A neglected partner in the healthy development of young children. In J. L. Aber, S. J. Bishop-Josef, S. M. Jones, K. T. McLearn, & D. A. Phillips, *Child development and social policy: Knowledge for action* (pp. 233-248). Washington, DC: American Psychological Association.
- McCarthy, J.; Marshall, A.; Irvine, M.; Jay, B. 2004. An Analysis of Mental Health Issues in States' Child and Family Service Reviews and Program Improvement Plans. Washington, DC: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development and American Institutes of Research.
- Morreale, M.C. & English, A. (2003). Eligibility and enrollment of adolescents in Medicaid and SCHIP: Recent progress, current challenges. *Journal of Adolescent Health*, 32(6), 25-39.
- National Alliance for the Mentally Ill. (1999). Families on the brink: The Impact of ignoring children with serious mental illness, results of a national survey of parents and other caregivers. NAMI.
- National Center for Children in Poverty. (2006). *Children's mental health: Facts for policy makers*. Retrieved from http://www.nccp.org/publications/pub_687.html
- National Health Law Program. (2012). Addressing adolescent health: The role of Medicaid, CHIP, and the ACA. Retrieved from: file:///C:/Users/MonicaF/Downloads/Adolescent_Health_Issue_Brief_11.5.12.pdf
- National Health Policy Forum. (2004, June 4). Children with mental disorders: Making sense of their needs and systems that help them. Washington DC: The George Washington University.
- Newacheck, P., Hughes, D., Hung, Y. Y., Wong, S., & Stoddard, J. (2000). The unmet health needs of America's children. *Pediatrics*, 105, 989-997.
- Newacheck, P., Park, M.J., Brindis, C.D, Biehl, M. & Irwin, C.E. (2004). Trends in private and public health insurance for adolescents, *The Journal of the American Medical Association*, 291(10): 1231-1237.
- New Freedom Commission on Mental Health. (2003, November). *The President's New Freedom Commission on Mental Health: Transforming the Vision*. The Carter Center: Nineteenth Annual Symposium on Mental Health Policy. Retrieved from: <http://www.cartercenter.org/documents/1701.pdf>
- Olfson, M., Schaffer, D., Marcus, S. C., & Greenberg, T. (2003). Relationship between antidepressant medication treatment and suicide in adolescent. *Archive General Psychiatry*, 60, 978-982.
- Pear, R. (2003, September 1). Mental care poor for some children in state custody. *N.Y. Times*. Retrieved from <http://www.nytimes.com/2003/09/01/us/mental-care-poor-for-some-children-in-state-custody.html>
- President's Commission on Excellence in Special Education (2002, July 1). A new era: Revitalizing special education for children and their families. Retrieved from: <https://education.ucf.edu/mirc/Research/President's%20Commission%20on%20Excellence%20in%20Special%20Education.pdf>
- Redden, S. C., Forness, S. R., Ramey, C., Ramey, S., Brezausek, C. M., & Kavale, K. (2003). Head Start children with a putative diagnosis of ADHD: A four-year follow-up of special education placement. *Education and Treatment of Children*, 26, 208-223.

- Ringel, J. S., & Sturm, R. (2001). National estimates of mental health utilization and expenditures for children in 1998. *Journal of Behavioral Health Services*, 28(3), 319-333.
- Rupp, A., Gause, E. M., & Regier, D. A. (1998). Research policy implications of cost-of-illness for mental disorders. *Behavioral Journal of Psychiatry*, 36, 19-25 (suppl).
- Seltzer, T. (2003). *Suspending disbelief: moving beyond punishment to promote effective interventions for children with mental or emotional disorders*. Washington, D.C.: Bazelon Center for Mental Health Law.
- Simmons, T. J. (2008). Relinquishing custody in exchange for mental healthcare services: Undermining the Adoption and Safe Families Act's promise of reasonable efforts towards family preservation and reunification. *Journal of Law & Family Studies*, 10, 377-400.
- Society for Adolescent Medicine. (2004). Access to health care for adolescents and young adults. *Journal of Adolescent Health*, 35, 342-344.
- Stein, R.E.K. (2011). The 1990s: A decade of change in understanding children with ongoing conditions. *Archives of Pediatric Adolescent Medicine*, 165(10), 880-883.
- Strozer, J., Juszczak, L., & Ammerman, A. (2010). 2007-2008 National School-Based Health Care Census. Washington, DC: National Assembly on School-Based Health Care
- Sturm, R., Ringel, J. S., & Andreyeva, T. (2003). Geographic disparities in children's mental health care. *Pediatrics*, 112:e308.
- Substance Abuse and Mental Health Services Administration. (2006). *Definitions and terms relating to co-occurring disorders*. Rockville: Department of Health and Human Services.
- Substance Abuse and Mental Health Services Administration. (2006, May/June). Community-based care helps children. *SAMHAS's Award-Winning Newsletter*, 14(3). Retrieved from http://www.samhsa.gov/samhsa_news/VolumeXIV_3/article.htm
- Szilagyi, P. G., Shenkman, E., Brach, C., LaClair, B. J., Swigonski, N., & Dick, A. (2003). Children with special needs enrolled in the State Children's Health Insurance Program (SCHIP): Patient characteristics and health care needs. *Pediatrics*, 112 (Suppl.), e508-e520.
- Teplin, L. A., Abram, K. M., McClelland, G. M., Dulcan, M. K., & Mericle, A. A. (2002). Psychiatric disorders in youth in juvenile detention. *archives of General Psychiatry*, 59, 1133-1143.
- Texas Department of Family and Protective Services . (2007). *Child abuse and neglect central registry*. Retrieved from Texas Department of Family and Protective Services: http://www.state.tx.us/child_care/other_child/
- Texas Department of Family and Protective Services (DFPS). (2014). *Minimum standards for general residential operations*. Retrieved from http://www.dfps.state.tx.us/documents/child_care_standards_and_regulations/748_GRO.pdf
- Texas Department of Mental Health and Mental Retardation. (1996). *Community Mental Health and Mental Retardation Center Performance Contract Notebook: Fiscal Year 1997*. Austin, TX: Texas Department of Mental Health and Mental Retardation.
- Texas Department of State Health Services. (2014a). *Texas Health Steps EPSDT*. Retrieved from Texas Department of State Health Services: <http://www.dshs.state.tx.us/thsteps/providers-EPSDT.shtm>
- Texas Department of State Health Services. (2014b). *Youth Empowerment Services*. Retrieved from Texas Department of State Health Services: <http://www.dshs.state.tx.us/mhsa/yes/>
- Texas Department of State Health Services. (2010). *CPS and refusal to accept parents' responsibility*. Retrieved from Texas Department of State Health Services: [http://texanscareforchildren.org/Images/Interior/mh%20 forum/rapr%20 background.pdf](http://texanscareforchildren.org/Images/Interior/mh%20forum/rapr%20background.pdf)
- Texas Institute for Excellence in Mental Health, School of Social Work, Center for Social Work Research, The University of Texas (2010). *Youth Empowerment Service Program Evaluation*. Retrieved from: <http://www.dshs.state.tx.us/mhsa/yes/>
- Texas Juvenile Justice Department (2014). *Special Needs Diversionary Program (SNDP)*. Retrieved from <http://www.tjjd.texas.gov/services/sndp.aspx>.
- Texas Medical Association. Static Fee Schedules. Retrieved from: <http://public.tmhpa.com/FeeSchedules/StaticFeeSchedule/FeeSchedules.aspx>
- Texas Statewide Health Coordinating Council. (n.d.) 2011-2016 Texas State Health Plan. Retrieved from: <file:///C:/Users/MonicaF/Downloads/SHP2011-2016.pdf>
- Texas System of Care. (2014). *Wraparound services*. Retrieved from Texas System of Care: <http://www.txsystemofcare.org/wraparound/>
- The President's New Freedom Commission on Mental health. (2003). *Achieving the promise: Transforming mental health care in America (Report No.: SMA-03-3832)*. Rockville, MD: U.S. Department of Health and Human Services.

- Thompson, K. M. (2004). An adult recidivism outcome evaluation of North Dakota's juvenile drug court. Fargo, ND: North Dakota State University.
- TTARA. (2012, January). An Introduction to School Finance in Texas. Austin, TX. Retrieved from: <http://www.ttara.org/files/document/file-4f1732f763446.pdf>
- U.S. Department of Health and Human Services. (2014). *Glossary of Terms*. MD: U.S. Department of Health and Human Services, Agency for healthcare research and quality. Retrieved from <http://www.surgeongeneral.gov/library/mentalhealth/home.html>
- U.S. Department of Health and Human Services. (2014b). *What is Integrated Behavioral Health Care*. MD: U.S. Department of Health and Human Services, Agency for healthcare research and quality. Retrieved from <http://integrationacademy.ahrq.gov/atlas/What%20Is%20Integrated%20Behavioral%20Health%20Care>
- U.S. Department of Health and Human Services (2010). *Most Children in Nine States are Not Receiving All Required Preventative Screening Services*. Retrieved from <http://oig.hhs.gov/oei/reports/oei-05-08-00520.pdf>
- U.S. Department of Health and Human Services. (1999). *Mental Health: A report of the Surgeon General*. MD: U.S. Department of Health and Human Services. Retrieved from <http://effectivehealthcare.ahrq.gov/index.cfm/glossaryofterms/?pageaction=showterm&termid=24>
- U.S. Public Health Service. (2001). *Mental health: Culture, race, and ethnicity (a supplement to mental health: A report of the Surgeon General)*. Rockville, MD: U.S. Department of Health and Human Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.
- U.S. Health and Human Services . (1999). *Mental health: A report of the Surgeon General*. Rockville, MD: U.S. Department of Health and Human Services Administration, Center for Mental Health Services, National Institutes of Health, National institute of Mental Health.
- United States General Accounting Office. (2003). Child welfare and juvenile justice, several factors influence the placement of children solely to obtain mental health services. Washington, DC: GAO.
- Vermeiren R. (2003). Psychopathology and delinquency in adolescents: A descriptive and developmental perspective. *Clinical Psychology Review*, 23, 277–318.
- Wang, P. S., Berglund, P., & Olfson, S. (2005). Failure and delay in initial treatment contact after first onset of mental disorders.
- Warfield, M.E. & Gulley S.(2006). Unmet need and problems accessing specialty medical and related services among children with special health care needs. *Maternal and Child Health Journal*, 10(2):201-216.
- Wasserman, G.A., Ko S.J. & Reynolds, L.S. (2004). Assessing the mental health status of youth in juvenile justice settings. *Juvenile Justice Bulletin*, 1–7. Retrieved from: www.ojp.usdoj.gov/ojdp.
- World Health Organization (WHO). (2001). *Global Burden Of Disease (GBD) 2001 estimates*. Retrieved from World Health Organization: http://who.int/healthinfo/global_burden_diseases/estimates_regional_2001/en/
- Zima BT, Bussing R, Yang X , & Belin TR. (2000). Help-seeking steps and service use of children in foster care. *Journal of Behavioral Health Services and Research*, 27(3):271-85.
- Zito, J. M., Safer, D. J., & DosReis, S. (2002). Rising prevalence of antidepressants among US youth. *Pediatrics*, 109, 721-727.

APPENDIX A: GLOSSARY

Child Abuse Registry

Child abuse registries vary across states and may contain reported or substantiated cases of child abuse and neglect. In Texas, the registry consists only of information gathered during investigations of child abuse and neglect in cases with a disposition of "reason to believe" and the person had a role of designated perpetrator or sustained perpetrator (40 TAC 700.104). The state of Texas registry is maintained by the Department of Family Protective Services (DFPS) automated system, Information Management Protecting Adults and Children in Texas (IMPACT) (Texas Department of Family and Protective Services, 2007).

Community-Based Care Services

Community-Based Care refers to treatment in the home community rather than inpatient and residential facilities. This type of care emphasizes an active role for family members and requires close collaboration between providers and families (U.S. Department of Health and Human Services Administration for Children & Families, 2014).

Evidence-Based Practice

Evidence-based practice refers to using the best available research to make decisions about client care. Treatment providers use research and their clinical experience in conjunction with the unique needs of the client to provide care (U.S. Department of Health and Human Services, 2014)

Externalizing Behavior

Externalizing behavior problems are evidenced by the child's outward behavior and involve negatively acting on the external environment (Campbell, Shaw, & Gilliom, 2000; Eisenberg et al., 2001). In the research literature, examples of externalizing behaviors include aggression and destruction of property (Jiangong, 2004).

Internalizing Behavior

Internalizing behavior problems affect the child's internal psychological environment. Examples of internalizing behaviors include anxiety, depression, and withdrawing (Jiangong, 2004).

Least Restrictive Environment

Least restrictive environment refers to a setting in which an individual maintains the greatest degree of freedom and self-determination appropriate for the level of care the individual needs while receiving services.

Relinquishment

Relinquishment refers to the act of parents turning over custody and care of their children to State authorities. In the context of this study, this term generally refers to situations where a family has relinquished custody based on an inability to provide mental health care for their child or seek access to additional mental healthcare for their child.

Residential Treatment

Residential Treatment is provided in congregate settings where multiple youth (generally more than six) live and receive services. General residential operations provide treatment and 24 hour care for children with emotional disorders (Texas Department of Family and Protective Services, 2014).

Serious Emotional Disturbance

A child with a serious emotional disturbance is an individual 18 years or younger that currently or at any time during the past year been diagnosed with a mental, behavioral, or emotional disorder. The disorder will have had to exist for a specified duration according to DSM-5 diagnostic criteria. The disorder must result in functional impairment that interferes with the child's functioning in social, educational, and family realms. Lack of proper social and behavioral skill, as well as inhibited cognitive, communication, and adaptive skills will be evident (Substance Abuse and Mental Health Services Administration , 2006). In Texas' statute, serious emotional disturbance is called "severe" emotional disturbance.

Serious Mental Illness

Serious mental illness (SMI) is defined as an individual 18 years or older that currently or at any time during the past year been diagnosed with a mental, behavioral, or emotional disorder. The disorder will have had to exist for a specified duration according to DSM-5 diagnostic criteria. The disorder must result in functional impairment that interferes with one or more life activities such as: daily living skills, instrumental living skills, and family social functioning (Substance Abuse and Mental Health Services Administration , 2006).

Wraparound Services

According to Texas System of Care (2014), wraparound services are a practice model that targets emotional or behavioral needs of children, youth, and families. Utilizing an ecological model, wraparound services incorporate resources from the family, mental health professionals, medical professionals, and community members. Wraparound services incorporate resources and skills from multiple sources to create a plan of care that fits families' specific needs and resources (Texas System of Care, 2014). Further explanations of wraparound services can be found at <http://www.nwi.pdx.edu/wraparoundbasics.shtml>

APPENDIX B: AVAILABLE SERVICES BY STATE

Available Services and Policies by State

States vary greatly in their policies on parental relinquishment. While thirteen states do not allow state agencies to require relinquishment to gain access to mental health services (Colorado, Connecticut, Idaho, Indiana, Iowa, Maine, Massachusetts, Minnesota, North Dakota, Oregon, Rhode Island, Vermont, and Wisconsin), other states give the court's jurisdiction to order mental health services (Wisconsin, Iowa) (Giliberti and Schulzinger, 2000; GAO, 2003). Other states have attempted to enforce federal funding options to provide mental health services (Giliberti and Schulzinger, 2000). In most states when a child is relinquished to receive mental health services, the case is treated the as an abuse and neglect case, resulting in stigma for the family (Goodman, 2001).

Table 5. Available services by state

State	Past Statute	Current Statute	Current Text	Additional Background
CO	C.R.S. 19-3-701(1)	C.R.S. 27-67-101	The Child Mental Health Treatment Act (CMHTA)	The current statute was enacted in 1999 through House Bill 99-1116. The Act Allows families to access community, residential and transitional treatment services for their child without requiring a dependency and neglect action, when there is not substantiated child abuse or neglect. Eligibility requires that the child have a mental illness, be under the age of 18, and must be at risk of out-of-home placement or at risk of further involvement with the department of human/social services. The act applies to children regardless of their Medicaid eligibility.
CT	Public Act 97-272	Public Act 97-272		Sec. 4. There shall be no requirement for the Department of Children and Families to seek custody of any child or youth with mental illness, emotional disturbance, a behavioral disorder or developmental or physical disability if such child is voluntarily placed with the department by a parent or guardian of the child for the purpose of accessing an out-of-home placement or intensive outpatient service, including, but not limited to, residential treatment programs, therapeutic foster care programs and extended day treatment programs, except as permitted pursuant to sections 17a-101g and 46b-129 of the general statutes. Commitment to or protective supervision or protection by the department shall not be a condition for receipt of services or benefits delivered or funded by the department.
ID	I.C. 16-2406		The Children's Mental Health Services Act	On July 1, 1998, the Children's Mental Health Services Act took effect. This act states that children with Serious Emotional Disturbance (serious emotional disturbance) will be served without parents relinquishing custody
ME	Title 22, M.R.S 4004-A	Title 22, M.R.S. 4004-A	Child and Family Service and Child Protection Act	If the following conditions are met, the department and a custodian may enter into a mutual agreement in which the custodian retains custody of the child and the department agrees to provide services to the child. A. The department finds that staying in the custodian's home would be detrimental to the welfare of the child. [1993, c. 724, §1]. The department finds that, absent a mutual agreement, the child is at risk of entering the child protection system or the juvenile justice system.
ND	N.D. Cent. Code 50-06-06.13	Statute remains as of 2014	Public Welfare: Department of Human Services	50-06-06.13. Treatment services for children with serious emotional disorders. The department shall establish in all human service regions a program to provide out-of-home treatment services for a Medicaid-eligible child with a serious emotional disorder. The department may not require a parent or legal guardian to transfer legal custody of the child in order to have the child placed in an out-of-home treatment program when the sole reason for the placement is the need to obtain services for the child's emotional or behavioral problems. With departmental approval, a parent with legal and physical custody of the child may obtain treatment services for the child through the program. A parent without physical custody of a child, who disagrees with a child's treatment under this section, may request a judicial determination regarding the child's treatment.

State	Past Statute	Current Statute	Current Text	Additional Background
OR	ORS 418.312	Statue remains as of 2011		(1) The Department of Human Services may not require any parent or legal guardian to transfer legal custody of a child in order to have the child placed under ORS 418.205 (Definitions for ORS 418.205 to 418.310 and 418.992 to 418.998) to 418.310 (Application of statutes to institutions caring for adults and children), 418.480 (Purchase of care defined) to 418.500 (Out-of-state care for children) and 418.992 (Civil penalty) to 418.998 (Disposition of penalties) in a foster home, group home or institutional child care setting, when the sole reason for the placement is the need to obtain services for the child’s emotional, behavioral or mental disorder or developmental or physical disability. In all such cases, the child shall be placed pursuant to a voluntary placement agreement. When a child is placed pursuant to a voluntary placement agreement, the department shall have responsibility for the child’s placement and care. When a child remains in voluntary placement for more than 180 days, the juvenile court shall make a judicial determination, within the first 180 days of the placement, that the placement is in the best interests of the child. In addition, the juvenile court shall hold a permanency hearing as provided in ORS 419B.476 (Conduct of hearing) no later than 14 months after the child’s original voluntary placement, and not less frequently than once every 12 months thereafter during the continuation of the child’s original voluntary placement, to determine the future status of the child.
RI	R.I. Gen. Laws 14-1-11.1	Statue remains as of 2013	Delinquent and Dependent Children: Proceedings in Family Court	§ 14-1-11.1 Commitment of voluntary placements. – (a) The department of children, youth, and families shall petition the family court and request the care, custody, and control of any child who is voluntarily placed with the department for the purpose of foster care by a parent or other person previously having custody and who remains in foster care for a period of twelve (12) months. However, there shall be no requirement for the department to seek custody of any child with an emotional, behavioral or mental disorder or developmental or physical disability if the child is voluntarily placed with the department by a parent or guardian of the child for the purpose of accessing an out-of-home program for the child in a program which provides services for children with disabilities, including, but not limited to, residential treatment programs, residential counseling centers, and therapeutic foster care programs.
IA	C.I 232.178	C.I 232.178	Juvenile Code: Juvenile Justice	The petition shall describe the child’s emotional, physical, or intellectual disability which requires care and treatment; the reasonable efforts to maintain the child in the child’s home; the department’s request to the family of a child with an intellectual disability, other developmental disability, or organic mental illness to determine if any services or support provided to the family will enable the family to continue to care for the child in the child’s home; and the reason the child’s parent, guardian, or custodian has requested a foster family care placement. The petition shall also describe the commitment of the parent, guardian, or custodian in fulfilling the responsibilities defined in the case permanency plan and how the placement will serve the child’s best interests.

APPENDIX C: CAREGIVER SURVEY FINDINGS

Methods

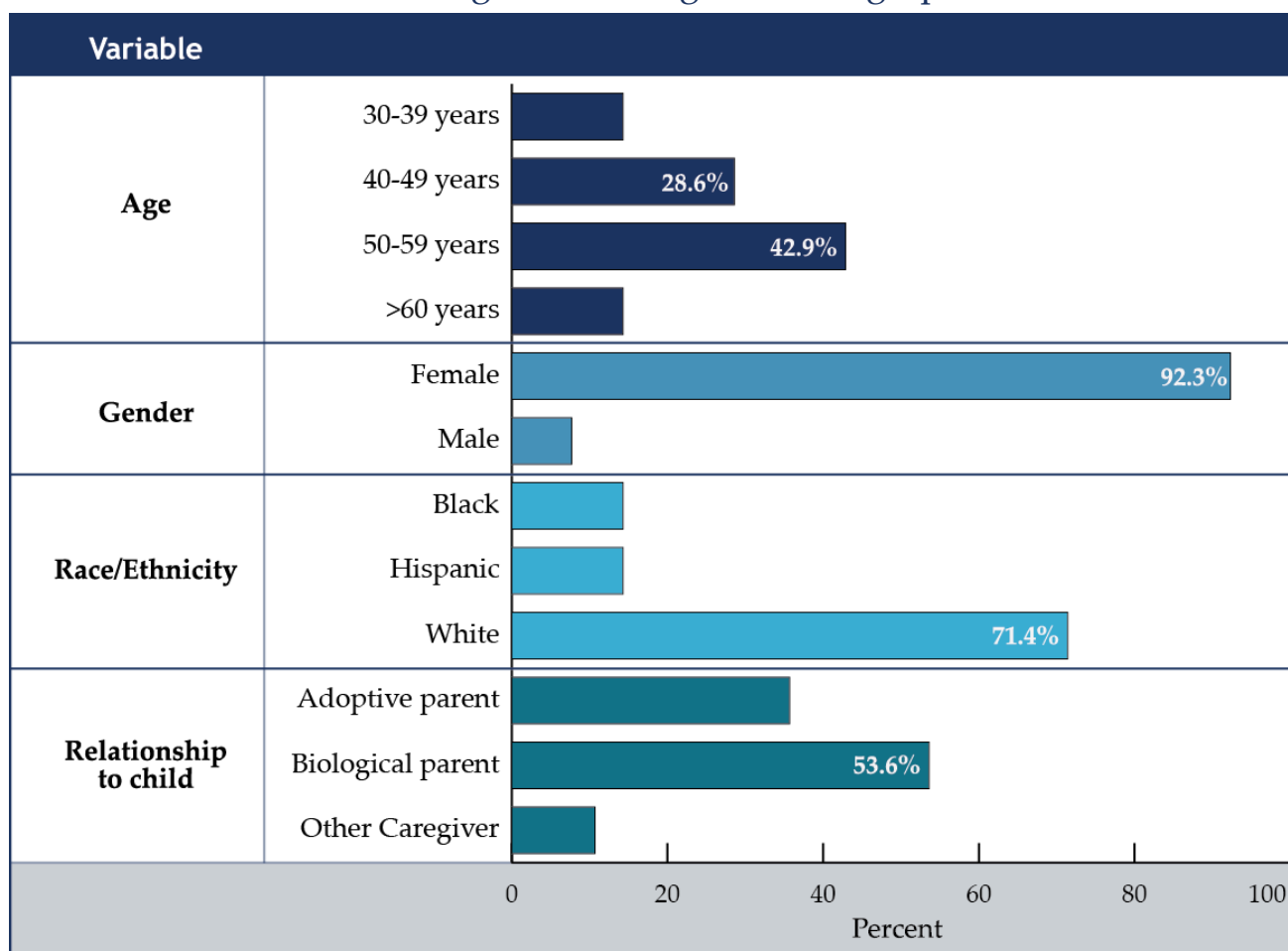
An online survey was available to parents and caregivers of children with serious emotional disturbance in May of 2014. The survey was advertised to parents through various parent and advocacy listserves, the child abuse and runaways hotlines and referrals from advocates. All parents were given the study website where they could read about the study and click a link to participate. 47 parents attempted to complete the survey, but only 28 caregivers actually completed the survey.

Participants

Caregiver demographics

The majority of caregivers (72%) were between the ages of 40 and 59. They were predominately female (92%) and white (71%). Of the participants, 53.6% were biological parents and 36% were adoptive parents. Figure 3 below provides a breakdown of participating caregiver demographics.

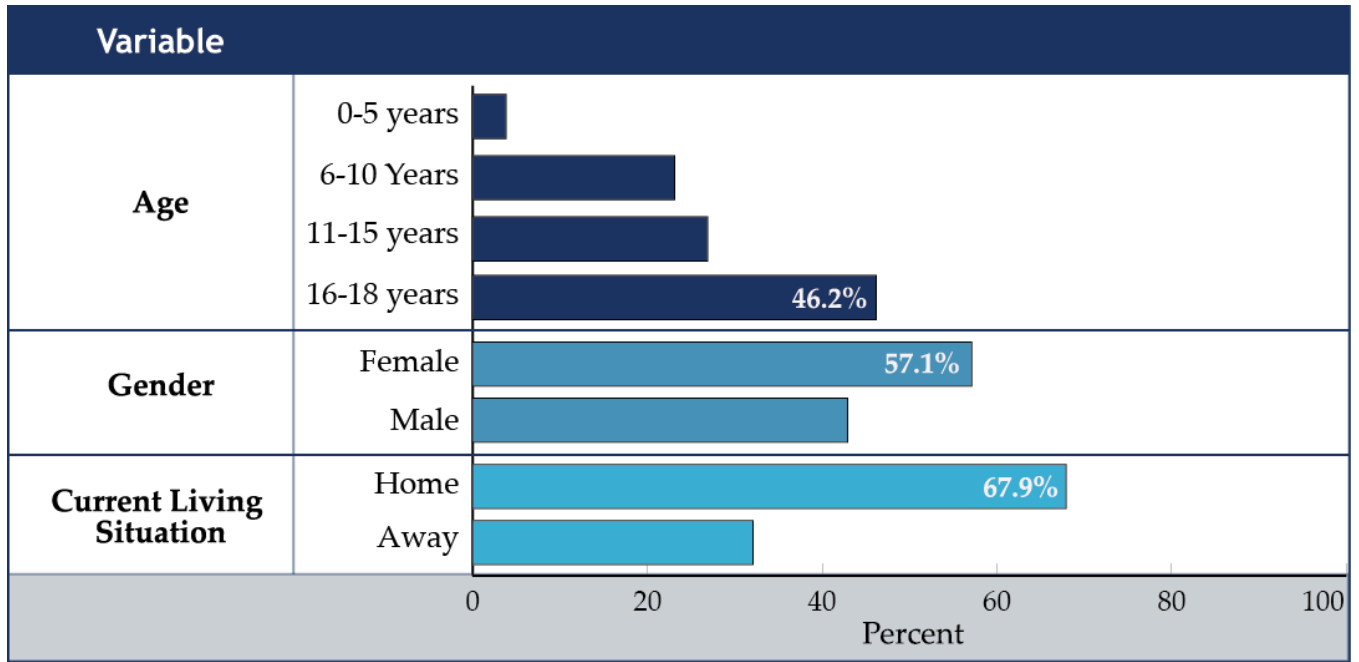
Figure 3. Caregiver demographics



Child demographics

Caregivers provided the age, gender, and living situation of their child having a serious emotional disturbance. Almost half of the children were between ages 15 and 18. Of the children with serious emotional disturbance, 57.1% were female and 67.9% were currently living at home with their caregiver. See Figure 4 for a breakdown of child demographics.

Figure 4: Child demographics



Child Insurance

Caregivers reported that their children were mainly insured over the past 12 months through private insurance (36%) and Medicaid/CHIP (46%). Only one caregiver reported that her child had no insurance over the past 12 months. See Table 7 below.

Table 6: Child insurance over the past 12 months

Insurance	Frequency	Percent
Private Insurance	10	35.7
Medicaid/CHIP	13	46.4
Other	1	3.6
Private + Medicaid	3	10.7
No Insurance	1	3.6

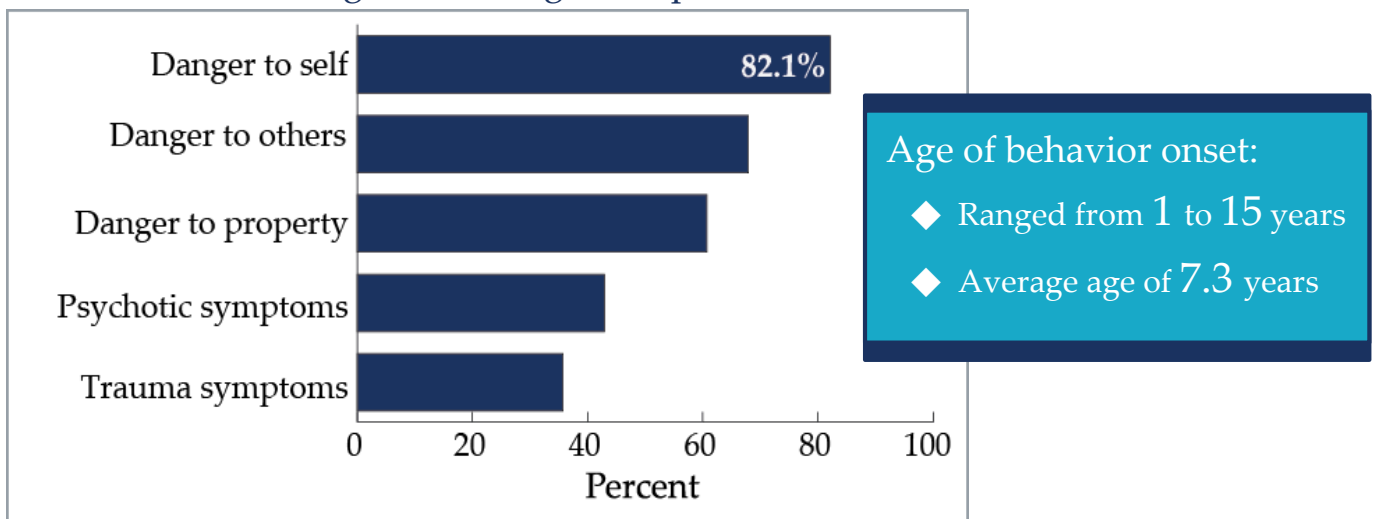
Child Behaviors

Caregivers were asked to identify behaviors their child had exhibited over the past twelve months. Behaviors were grouped under six categories. A description of each category is shown in Table 8 below. Caregivers most often reported their child exhibiting behaviors considered to be dangerous to self and/or dangerous to others (see Figure 6 below). The age at which the caregivers first noticed or felt concerned about their child’s behaviors ranged from 1 to 15 with the average age of 7.3 years old.

Table 7. Behavior categories and descriptions

Behavior	Description
Danger to self	Behaviors could include cutting or other self-mutilation, suicidal ideation or attempt, running away, inappropriate sexual behavior that puts self at risk, eating disorders, extreme tantrums or substance abuse
Danger to others	Behaviors could include threatening to harm or harming family members, peers, animals or others; inappropriate sexual behavior that puts others at risk, or extreme aggression
Danger to property	Behaviors could include destroying personal or public property, setting fires, stealing or urinating/defecating in areas other than the bathroom
Psychotic symptoms	Behaviors could include loss of contact with reality, delusions or hallucinations
Trauma symptoms	Behavior following exposure to trauma that could include flashbacks, dissociation, significant over or under responsiveness, panic or disruption in basic capabilities like sleeping, eating, elimination or impulse control

Figure 5. Caregiver reported child behaviors



Caregiver strain

Caregiver strain is defined as the impact of additional day to day demands that caregivers providing for children with emotional and behavioral disorders which can result in family disruption, interrupted work, loss of personal time, worry, and fatigue (Brannan, Athay, & Vides de Andrade, 2012). Brannan et al. (2003) conducted a study on the relationship between caregiver strain and mental health service utilization of a child. Findings from their study suggest that children of caregivers who report higher levels of caregiver strain are more likely to use more restrictive services and incur higher levels of costs.

In this study, 14 caregivers completed Brannan et al.'s (2012) Caregiver Strain Questionnaire-SF7, a validated measure that examines objective and subjective internalizing strain. Objective strain refers to observable negative events such as disruption of family relationships. Subjective internalized strain refers to negative feelings a caregiver may experience such as worry or sadness. Caregivers rated seven items on a scale from 1 "Not at all a problem" to 5 "Very much a problem" based on how much each item was a problem as a result of their child's serious emotional disturbance in the past 12 months. Mean scores for objective and subjective internalizing subscales were calculated. On average, caregivers are experiencing both high levels of subjective internalizing and objective strain as a result of raising their child with a serious emotional disturbance. Mean scores for both scales are shown below in Table 8.

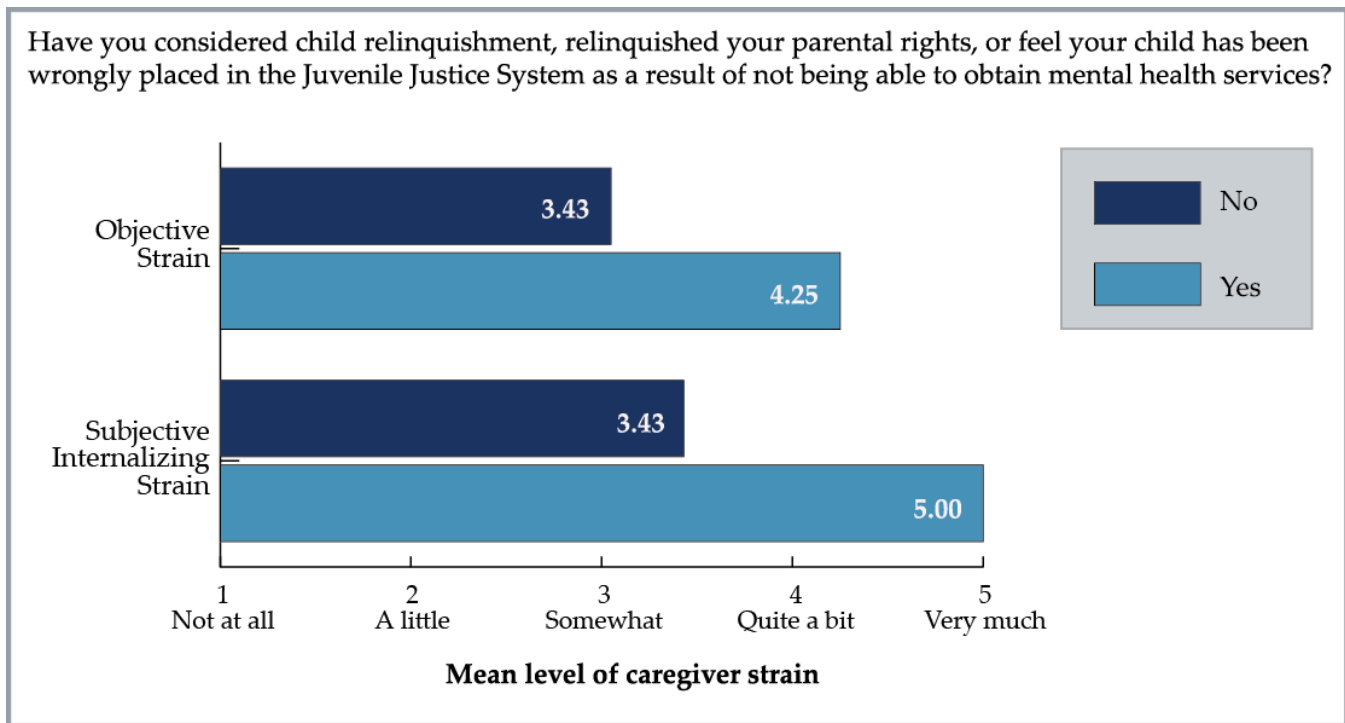
Table 8. Mean scores on objective and subjective internalizing strain

Caregiver Strain	Min	Max	Mean	SD
Objective Strain	1.75	5.00	3.39	1.03
Subjective Internalizing Strain	2.00	5.00	3.88	0.99

Child relinquishment and caregiver strain

Little information is known about the relationship between caregiver strain and child relinquishment. In this study, caregivers were asked if they had considered giving up their parental rights, had given up their parental rights, or felt their child had been wrongly placed in the juvenile justice system because no other mental health services were available for their child. A total of 4 out of 14 (29%) caregivers indicated "yes" to at least one of these statements. There was a statistically significant correlation between objective caregiver strain (.545) and subjective internalizing strain (.740) and the consideration of relinquishment, relinquishment, or placing a child in the juvenile justice system because there were no other options. Further exploration is advised due to small sample size and caution should be made when interpreting this relationship; however, caregiver strain may be an additional area of focus that providers working with families of children with SEDs can evaluate and address. Figure 6 below presents mean objective strain and subjective internalizing strain scores by whether or not a caregiver had considered giving up their parental rights, had given up their parental rights, or felt their child had been wrongly placed in the juvenile justice system because no other mental health services were available for their child.

Figure 6. Differences in caregiver strain by relinquishment status



Service utilization

Caregivers of a child with a serious emotional disturbance often seek out medical and mental health services for their child. This study examined patterns of service use among caregivers. Caregivers were asked to identify services they had never used, attempted to use, used more than 12 months ago, and used in the past 12 months from a list of 44 services. All services listed fell into one of the following categories: inpatient/residential services, crisis services, outpatient services, school services, family services, and informal services. See Table 10 below for a summary of lifetime and 12 month service use by service type.

Table 9. Percentage of lifetime and 12 month service use by service type

Service type	Percent lifetime use	Percent use in past 12 months
Inpatient/residential services	79.2%	66.7%
Crisis services	70.8%	50.0%
Outpatient services	100.0%	100.0%
Intensive outpatient services (IOP/PHP)	55.0%	35.0%
School services	93.8%	62.5%
Family services	75.0%	62.5%
Juvenile justice correctional facility	25.0%	20.0%

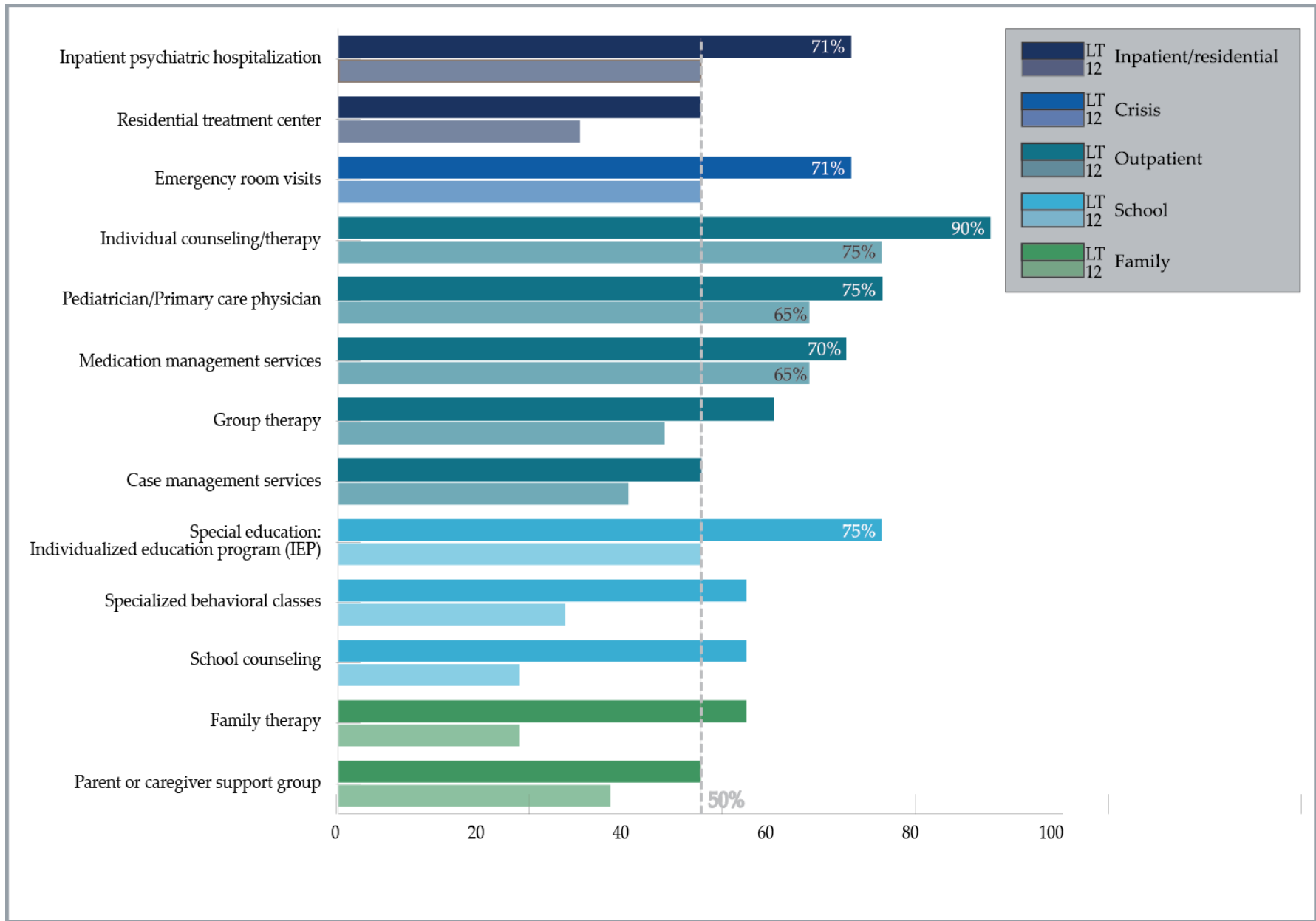
Lifetime use

Out of the 44 services, 13 were accessed by at least 50% of caregivers over their child's lifetime as a result of their child's behavior. Top lifetime use of inpatient, residential, and crisis services included inpatient psychiatric hospitalizations (71%), emergency room visits (71%) and residential treatment (50%). Outpatient services were the most common type of service accessed and included individual counseling or therapy (90%), pediatrician or primary care physician services (75%), and medication management services (70%). Top lifetime use of school services included special education individualized education programs (75%), specialized behavior classes (56%), and school counseling through a guidance counselor, social worker, or psychologist (56%). Family services used frequently included family therapy (56%) and caregiver support groups (50%).

Use in the past 12 months

Over the past 12 months, a total of 6 services were accessed by at least 50% of caregivers as a result of their child's behavior. Outpatient services included individual counseling or therapy (75%), pediatrician or primary care physician services (65%), and medication management (65%). Inpatient and crisis services included inpatient psychiatric hospitalization (50%) and emergency room visits (50%). Additionally, 50% of caregivers reported using special education services at school as a result of their child's behavior. Refer to Figure 7 for a summary of lifetime and past 12 month service use among frequently used services.

Figure 7. Percentage of lifetime (LT) and 12 month (12) use of common services* by service type



*For study purposes, a service is considered to be 'common' if at least 50% of caregivers reported using that service during their child's lifetime

Services never attempted for use

Several residential, crisis, and family services had never been attempted to be used by the majority of caregivers. Reasons for not attempting services are unknown but may include a lack of available services, inaccessibility, lack of awareness, stigma, and/or lack of need for a particular service. Table 11 below lists all services that had never been attempted to be accessed by at least 75% of caregivers in this study.

Table 10. Services never attempted to be used by at least 75% of caregivers

Service	Percent never attempted
Inpatient chemical dependency treatment	79.2%
Emergency respite care	75.0%
Group Home	75.0%
Emergency shelter	91.7%
Outpatient chemical dependency treatment	85.0%
Certified Family Partner services	75.0%
Wraparound Planning Process	75.0%

Frequency, costs, and usefulness of common services over the past 12 months Inpatient, residential, and crisis services

The frequency and cost of services varied based by insurance type and service over the last 12 months. Caregivers with private and public (Medicaid/CHIP) insurance types both accessed emergency rooms and psychiatric inpatient facilities. Residential treatment facilities, however, were accessed almost exclusively by caregivers covered by Medicaid, CHIP, or a combination of Medicaid and private insurance. The overall cost, frequency, and usefulness of inpatient, residential, and crisis services cannot be estimated due to the low response rate.

Outpatient Services

While outpatient services were utilized by all (100%) of the caregivers over the past 12 months, the frequency, type, cost, and usefulness of services varied significantly.

Pediatric/Primary Care. Caregivers reported using pediatric or primary care physician services anywhere from once a year to 12 times a year; however, one to two times a year appeared to be most common. Caregivers reported spending anywhere from \$0.00 to \$140.00 per year. Typically, there were no out-of-pocket costs for caregivers covered under Medicaid or CHIP. Additionally, 75% of caregivers who accessed pediatric or primary care physicians reported services to be very useful or extremely useful.

Individual counseling or therapy. The frequency and out-of-pocket costs associated with individual therapy appeared to vary depending on insurance coverage. For caregivers with private insurance only, the length of time in therapy over the past 12 months ranged from six months to the entire year. Sessions occurred at minimum once every two weeks and at maximum twice a week. Total sessions for the year ranged from 10 to 75 sessions. The out-of-pocket cost per session ranged from \$10.00 to \$133.00 per session, and the out-of-pocket total ranged from \$500.00 to \$10,000.00 over the past 12 months for privately insured individuals.

For individuals with Medicaid/CHIP or a combination of private insurance and Medicaid, the length of time in therapy over the past 12 months ranged from 1 day to 12 months. The frequency of sessions ranged from 1 time to twice a week. Total out-of-pocket costs ranged from \$0.00 to \$1,000.00 over the past 12 months (\$0.00 to \$125.00 per session). Overall, 18% of caregivers reported individual therapy services to be not useful. Approximately 45% reported therapy to be somewhat useful, and an additional 36% felt therapy was either very useful or extremely useful.

Medication management services. Caregivers accessed medication management services for their child between four and twelve times a year and were covered under Medicaid. For individuals privately insured, the total cost over the past 12 months ranged from \$100.00 to \$2,000.00. Approximately 75% of caregivers reported medication management services being somewhat useful. The remaining 25% of caregivers reported services being very useful.

Special Education Services

For children eligible for special education services, individualized educational programs are often provided through schools at no additional cost to families. The frequency that a child received services varied from daily to once every six months during the school year. Overall, 71% of caregivers felt special education was not useful or only somewhat useful to their child's overall well-being.

Family services

The most common family services accessed by caregivers in the past 12 months were caregiver support groups (38%) and family therapy (25%). Family therapy services were rated as not useful or somewhat useful by all caregivers who accessed them. Caregiver support groups were considered to be very or extremely useful by all caregivers who had used this service. The majority of caregivers (75%) also reported never attempting to use Certified Family Partner (CFP) services or Wraparound planning services. In the past year, only one participant had used CFP services; however, this caregiver rated the service as extremely useful.

Barriers

Caregivers identified access barriers and perception barriers that have prevented, delayed, or discouraged use of mental health services for their child. Most frequently, caregivers reported that 1) their child does not meet eligibility requirements for programs (50%) and 2) professionals often don't understand the needs of their child (50%). Approximately 43% of caregivers reported that not knowing where to go for help, a child not wanting help, lack of access to services in school, and not feeling like one's voice matters to service providers significantly prevented access to mental health services. See Table 12 below for a complete list of barriers.

Table 11. Percentage of caregivers indicating 'yes' to each barrier

Barrier	Percent
My child does not meet eligibility requirements for programs	50.00%
Professionals do not understand the needs of my child	50.00%
Services for my child are not available in my child's school	42.90%
I do not know where to go for help	42.90%
I do not feel my voice matters to service providers	42.90%
My child refuses treatment	42.90%
There is no space for my child in existing programs	35.70%
Long wait lists prevent my child from accessing existing services	35.70%
My insurance limits the length of time my child is able to receive services	28.60%
My insurance limits the type of services available for my child	28.60%
Lack of financial resources to pay for treatment and out-of-pocket costs	28.60%
Available services do not help my child	28.60%
I do not trust that providers will help my child	28.60%
My insurance is not accepted by local treatment providers	21.40%
My insurance denies coverage of needed services	21.40%
Services are provided at inconvenient appointment times	21.40%
I am afraid that my child would be labeled	21.40%
Mental health services are not available in my area	14.30%
Services are provided at an inconvenient location	14.30%
I do not have enough time	14.30%
Professionals who understand my family's cultural background and belief system are not available in my area	14.30%
I do not know when to go for help	14.30%
I do not feel included in my child's care	14.30%
I am afraid that my child would be hospitalized	7.10%
I am afraid that my child would be taken away	7.10%
I do not have transportation to get my child to and from appointments	0.00%
Language barriers prevent me from accessing care for my child	0.00%
My family is not supportive of treatment	0.00%
I am afraid of what my family and friends would think	0.00%

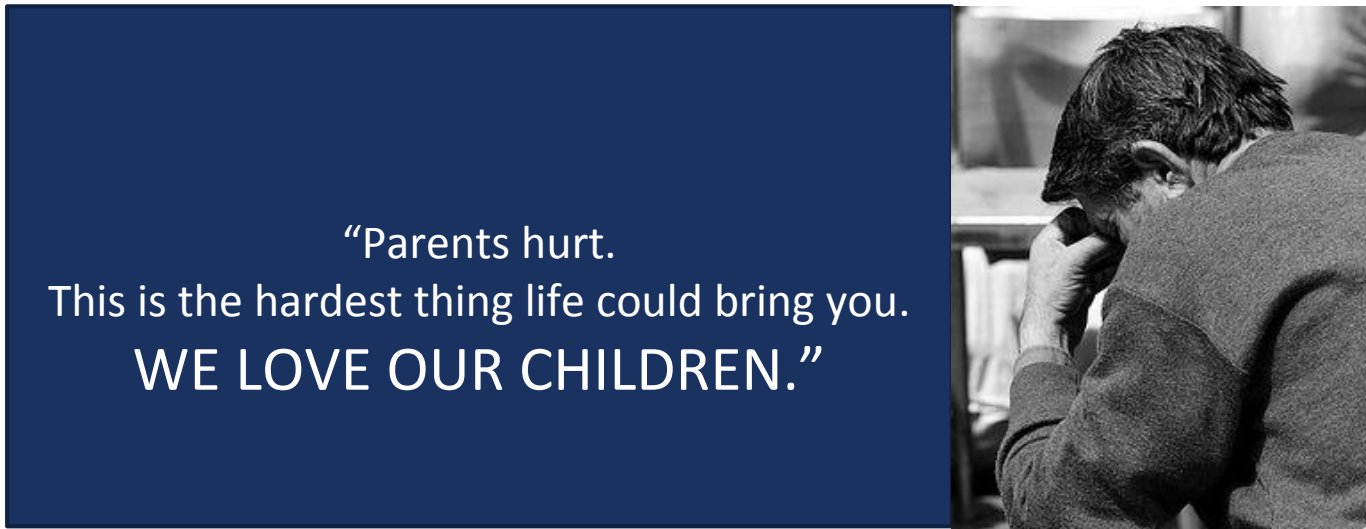
Caregiver themes and recommendations

At the end of the survey, caregivers were asked to 1) describe their most significant barrier, 2) provide recommendations, and 3) explain what they believe others need to understand about being a parent of a child with a serious emotional disturbance. Several themes emerged from their responses. See Table 13 below.

Table 12. Identified barriers and needs of caregivers

Barrier themes	Caregiver quotes describing barriers and needs
<p>Insurance driven services Insurance determines types of services families receive, length of services, and cost of services.</p>	<p>“We tried to get a case manager or social services in our home, but our income was too high.”</p> <p>“Without that [post-adoption Medicaid], I would have gone bankrupt, and then I, too, would have to had to give my child up just so she could get the services she needs.”</p> <p>Need: “Finding a therapist that will do in home behavior therapy & being able to use insurance to cover the cost.”</p> <p>Need: “The doctor needs to determine the appropriate discharge date rather than insurance.”</p>
<p>Lack of accessible/appropriate services Caregivers described not being able to access local quality services in an appropriate time frame that meet the child’s needs. Instead, families are often sent to the ER.</p>	<p>“Lack of beds for young children and she can never stay long enough for the medicine to take effect and see how it works and thus we are back again in about two months.”</p> <p>“The doctors are too busy to get her in right away, they just say go to the ER.”</p> <p>Need: “More access to quality services no matter what the economic circumstances of the family.”</p> <p>Need: “Need access to more support systems locally.”</p> <p>Need: “Nighttime or Saturday services hours for professionals”</p> <p>Need: “Therapists that understand Trauma, PTSD, and Reactive Attachment Disorders and how to heal the emotional wounds of the child.”</p>
<p>Lack of caregiver support and training Refers to a lack of support groups, training, and local services for caregivers to know how to help their child.</p>	<p>“They keep her a week, change her meds and then send her home. I am the one to have to read up on the meds, see if what she is acting is the result of the meds or the result of her illness. I am not trained to do this!!”</p> <p>“They do not understand how isolating it is for the family.”</p> <p>“There are so many pieces to the puzzle and they are never put together for a comprehensive plan.”</p> <p>Need: “Support group for parents.”</p> <p>Need: “To keep the parents informed and ask us what we think or what we feel our child needs.”</p>
<p>Juvenile justice is not the answer.</p>	<p>“Mentally ill do not belong in jail. Right now my child has three warrants for her arrest... All because her cases were not handled in</p>

Barrier themes	Caregiver quotes describing barriers and needs
<p>Caregivers discussed their child’s needs going unmet in the juvenile justice system. The juvenile justice system does not have the resources nor should it be the place where children with SEDs get help.</p>	<p>the mental health court. Even though the very first thing we said when we called the police was, ‘We have a mentally ill relative, who is out of control!’ ”</p> <p>“The juvenile system seems very unaware of resources and placement options for children that are not delinquents but rather suffer mental depression, reactive detachment disorder, and abuse from their past.”</p> <p>“The law does not support us when it comes to our daughter.”</p> <p>Need: “Our daughter needs intensive counseling in a very monitored setting.”</p> <p>Need: “Have a mandatory inpatient treatment after three police visits to the home.”</p>
<p>Lack of education around SEDs</p> <p>Caregivers discussed a lack of understanding and education around SEDs in the general public and within school systems.</p>	<p>“Mental illness is not talked about in the schools, and I wish someone at the school would be the child’s go-to person or an advocate at school.”</p> <p>Need: “More information on mental health for the community to be aware.”</p> <p>Need: “Make educating the public a priority.”</p> <p>Need: “For teachers to understand my child’s needs.”</p> <p>Need: “There are reasons for the ‘emotional disturbance’ label that should be recognized.”</p>



APPENDIX D: FAMILY CASE STUDIES

Methodology

Interviews were conducted with five families with children with severe emotional disturbance. The families were recruited through the dedicated website for the SB44 study distributed to families and advocates for children with severe emotional disturbance. The families interested in participating in an interview contacted the research team to schedule a time to meet. Each interview was conducted by a licensed social worker trained in data collection and research methods. Each interview was approximately an hour to an hour and a half in length and followed a semi-structured interview guide. The interviews were recorded and the transcripts were analyzed using conventional content analysis.

Interview Guide

1. What is your understanding of SB 44?
2. What is your experience working with families who have a child with a serious emotional disturbance?
3. How do families utilize the following services for a child with a serious emotional disturbance?
 - Treatment from doctors, counselors, or therapists
 - Outpatient and intensive outpatient
 - Emergency and inpatient psych treatment
 - Medication
 - Specialized programs or support at school
 - Juvenile justice or law enforcement
 - Availability of community support and resources
4. What services are most utilized in your community? Why?
5. What services do you feel your community is most in need of? Why?
6. What barriers do families face in utilizing services for a child with a serious emotional disturbance?
7. Have you discussed with or are you aware of families relinquishing care?
8. What support and resources do families need the most?
9. What policies are needed to support families?

Ten themes emerged through the analysis of the interview data. These include: early onset of concerning behaviors, experience with trauma, available services, needed services, effect on family, stigma of caring for a child with serious emotional disturbance, cost of services, treatment planning determined by insurance, relinquishment as last resort, concern for long-term outcomes.

Theme 1: Early onset of concerning behaviors

All five families reported concerns about their child's behavior prior to the age of five years old. Some recognized at the time of the behavior that they needed services, while others could see retrospectively some behaviors that were "red flags" at the time. While not all families sought services for their children at a very young age, by the time their children began kindergarten it became apparent that mental health services and school accommodations were necessary.

"When he was three my daughter's pediatrician goes, 'Something's wrong.' When he turned four and he threatened to kill [his father] and I and himself, I called (the pediatrician) up in tears and said, 'Okay, what? What now?'" and she goes, 'Something's wrong.'

Theme 2: Experience with trauma

Two of the five families that were interviewed reported their child had an early experience with trauma. Both of these families felt that their child's serious emotional disturbance were associated with their experience of trauma. Furthermore, both felt that the trauma had been addressed somewhat during treatment, but that the behaviors associated with serious emotional disturbance escalated to the point where they became the primary focus. They said that inpatient and residential services their children received did not address trauma-related concerns adequately which contributed to behavioral issues.

Theme 3: Available services

Several families discussed times of stability for their child. Often these times included a consistent and competent mental health provider. These providers were described as longer term and able to work with the family as well as the child. During times of stability, several parents reported integrated medical and behavioral management where everyone from school staff to a psychiatrist to a therapist was communicating and working together. Several families identified a loss of stability when a key provider was no longer able or willing to work with their child.

Services in schools were described as highly variable from year to year and school to school. Some parents shared very positive experiences with particular school staff, while others changed schools, often looking for a better fit for their child's needs.

Inpatient and residential care was also described as highly variable. Some providers were helpful and contributed to a phase of stability upon exiting care, and some seemed to make the child and family situation worse. Since many children cycle in and out of residential care in times of crisis throughout their youth, the inconsistency of treatment was a substantial source of stress for families.

Parent support groups were also mentioned by several families as a key place for information and commiseration. Connecting with others that understand the intensity of having a child with serious emotional disturbance was particularly important for families. One parent mentioned that she was a member of a parent support network that could provide respite care in times of need for each other.

Theme 4: Needed services

The most frequently cited need for families with a child with serious emotional disturbance was access to quality mental health and behavioral care. Each family described situations where they were unable to access the needed care for their child across the spectrum of care: psychological evaluation, therapy, medication management, residential care, and crisis intervention. Accessibility was hindered by a lack of available providers, wait-lists for services, and insurance or cost barriers. Several families felt they had exhausted their available options for care and were left with the choice between the ER, calling the police, and relinquishment to CPS.

In addition to access to quality care, all families discussed the need for consistent care. Several parents felt that even if they found quality care, it might be limited due to insurance requirements, staff turnover or unwillingness by the provider to continue with the case. When providers changed, families reported a feeling of having to start over building relationships and trust, as well as adjusting to a new treatment plan and/or medications.

Increased availability of training for working with children with serious emotional disturbance was also noted as a significant need. Training should include knowledge, skills and ways to support for parents and should be available for pediatricians, school staff, therapists, police and juvenile justice.

The need for respite care was also a common theme in the interviews. Parents described the difficulty in finding anyone who could provide care for their child. Without respite care, families described being increasingly isolated from “normal” activities, friends, and family. One parent described wanting to attend several trainings targeting skills for parenting a child with serious emotional disturbance, but could not find anyone with the skills or willingness to care for her 7 year old with serious emotional disturbance during the trainings.

Theme 5: Effect on family

All parents interviewed discussed the significant toll that addressing their child’s serious emotional disturbance had taken on the entire family. Some explained that it is often an “around the clock job” to monitor their child, manage medical and therapeutic appointments, school and case treatment meetings and crisis intervention. Families with other children in the home described high levels of stress and guilt associated with protecting siblings from emotional or physical harm, as well as providing a stable home environment. Each parent provided examples of limitations they experienced from not having friends and family over to the house, to not being able to take vacations. Most families also described extreme stress on their marriage, on employment, and their own mental health.

“We’re so exhausted from dealing with her on a day-to-day basis that the whole family is financially, emotionally, socially in physical crisis”

Theme 6: Stigma of caring for a child with serious emotional disturbance

Each parent reported a sense of isolation and judgment associated with their child's behavior and diagnoses. They described multiple scenarios where they felt shamed by professional providers, as well as neighbors, family, school staff, employers, or police. Each parent felt that very few people were able to understand the all-consuming nature of caring for a child with serious emotional disturbance. A couple families also discussed their reluctance to get early or progressively more intense treatment for their child due to the stigma of having a child with significant mental health needs.

"That's why the parents get so frustrated. They don't know what to do. They don't know how to help their kid. I believe that the majority of parents want the best for their kids, but they don't know why it's [treatments] not working. They just know it's not working. There's a lot of guilt placed on them by the system, by clinicians, by caseworkers, by everybody, by doctors, by family. That they've done something wrong, and that's why it's not working."

Theme 7: Cost of services

The out of pocket costs for services was a significant burden for all of the families. The families that participated in the interviews all had private insurance, but were faced with substantial expenses related to care, including co-pays for medication, inpatient and residential care, therapy, and ER costs.

"The last letter from the insurance says he's untreatable, so we're not going to help you. He's not going to go there, because it costs—the last time he was in [residential care] it cost over \$250,000. That was to the insurance company. To us, it was an \$8,000 copayment."

Theme 8: Treatment planning determined by insurance

Each family shared experiences with a change or stop in treatment due to insurance requirements. Children were often discharged from residential or inpatient treatment prior to stabilization because maximum insurance benefits had been met rather than successful treatment had been noted. Insurance also determined where a child could go for treatment. Even if a particular facility or provider had been helpful or unhelpful in the past, availability of insurance coverage was the determining factor in placement. Families reported spending a significant amount of time negotiating and advocating with their insurance carrier to receive needed services.

"I'm trying to get him help, but because of your insurance it's almost impossible."

Theme 9: Relinquishment as last resort

Each parent interviewed discussed relinquishment to CPS as an absolutely last resort. While relinquishment was unthinkable for some, most families interviewed could understand reaching a point of desperation for services to ensure the safety of their child and their family that would force them to consider relinquishment. One parent who had called CPS considering relinquishment described it as a clear sign of failure in multiple systems.

Theme 10: Concern for long-term outcomes

All five families shared grave concern for their children as they moved into adulthood. Two families reported that their child was currently incarcerated and the others predicted incarceration in the future. Several parents also discussed their fear that as their child moved into adulthood and services became more limited that the risk increased that the child would hurt themselves or someone else. Three families expressed their fear that their child would face an early death due to self-injury or impulsive risk-taking.

“That’s been a hard thing, to hear that and accept that and start trying to figure out what we’re going to do with him in our life and how are we going to help him? What’s available to help him to have a life, if any, other than being in prison or jail or dead? Yes, that’s where our next chapter of our life is and it’s terrible.”

APPENDIX E: STAKEHOLDER SURVEY FINDINGS

Methods

An online survey was available to stakeholders in May of 2014. The survey was advertised through various listserves for advocates, counselors/therapists, social workers and medical professionals. Stakeholders were given the study website where they could read about the study and click a link to participate. 58 stakeholders attempted to complete the survey with 31 stakeholders actually completing the survey.

Participants

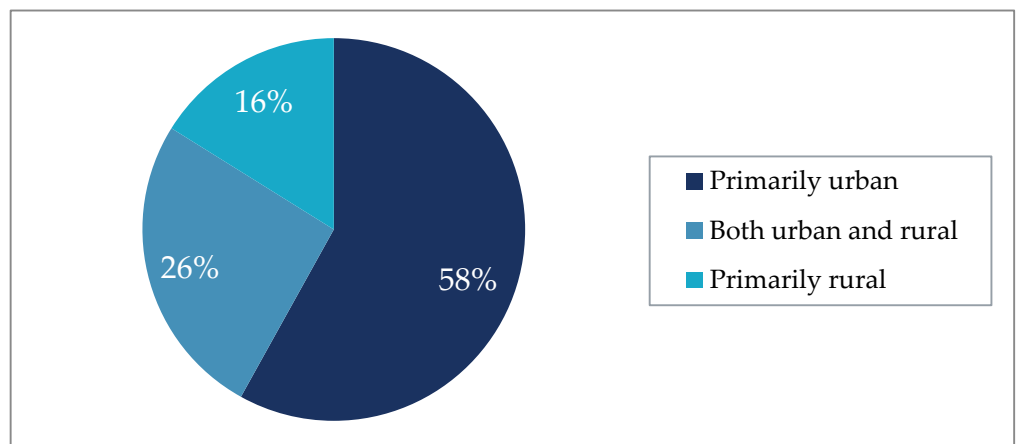
The majority were social workers (67.7%) and other licensed counselors (22.6%). Additionally, two psychologists, one psychiatrist and one occupational therapist completed the survey. A few stakeholders reported having additional professional roles including advocacy, case management, and research. The stakeholders ranged in years of professional experience from 2 to 40 years, averaging 12.1 years. See Table 14 below for a breakdown of stakeholder participation by years of experience

The majority of stakeholders worked in predominately urban communities (58.1%); however, 25.8% reported working in communities that were both urban and rural and 16.1% reported working in primarily rural communities. See Figure 8 below.

Table 13. Stakeholder participation by years of experience

Years of experience	Frequency (N)	Percent	Cumulative Percent
Less than 5 years	7	23.3	23.3
5 to 9 years	10	33.3	56.7
10 to 20 years	7	23.3	80.0
More than 20 years	6	20.0	100.0

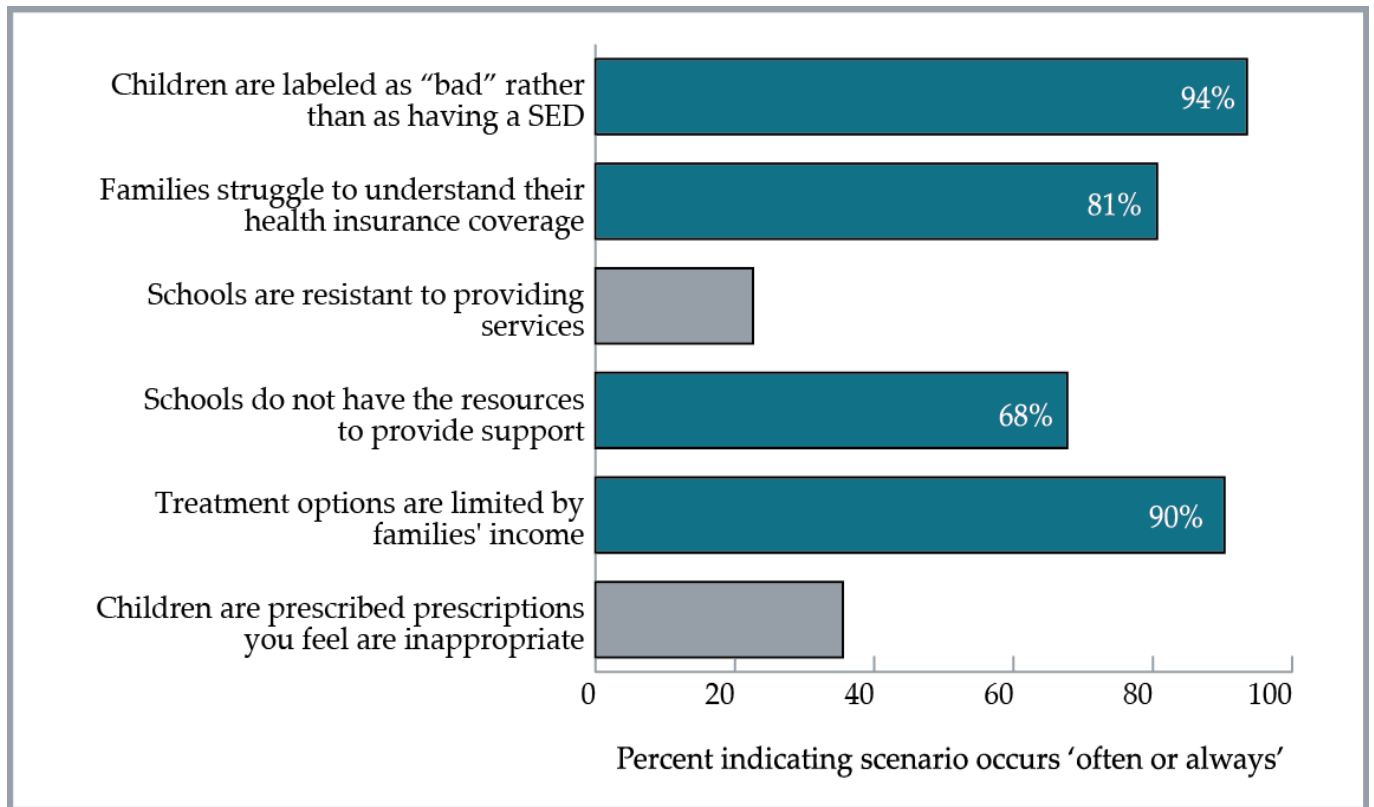
Figure 8. Stakeholder participation by community type



Scenarios impacting child outcomes

Stakeholders were asked to identify how frequently scenarios affecting children with SEDs occur in their area. In Figure 9, six scenarios that negatively impact outcomes of children with SEDs are listed. More than 60% of respondents selected “often or always” on four of the six listed negative scenarios. Based on findings, families are limited by income and available resources in addition to facing challenges in understanding insurance. Additionally, children with SEDs appear to be stigmatized and labeled.

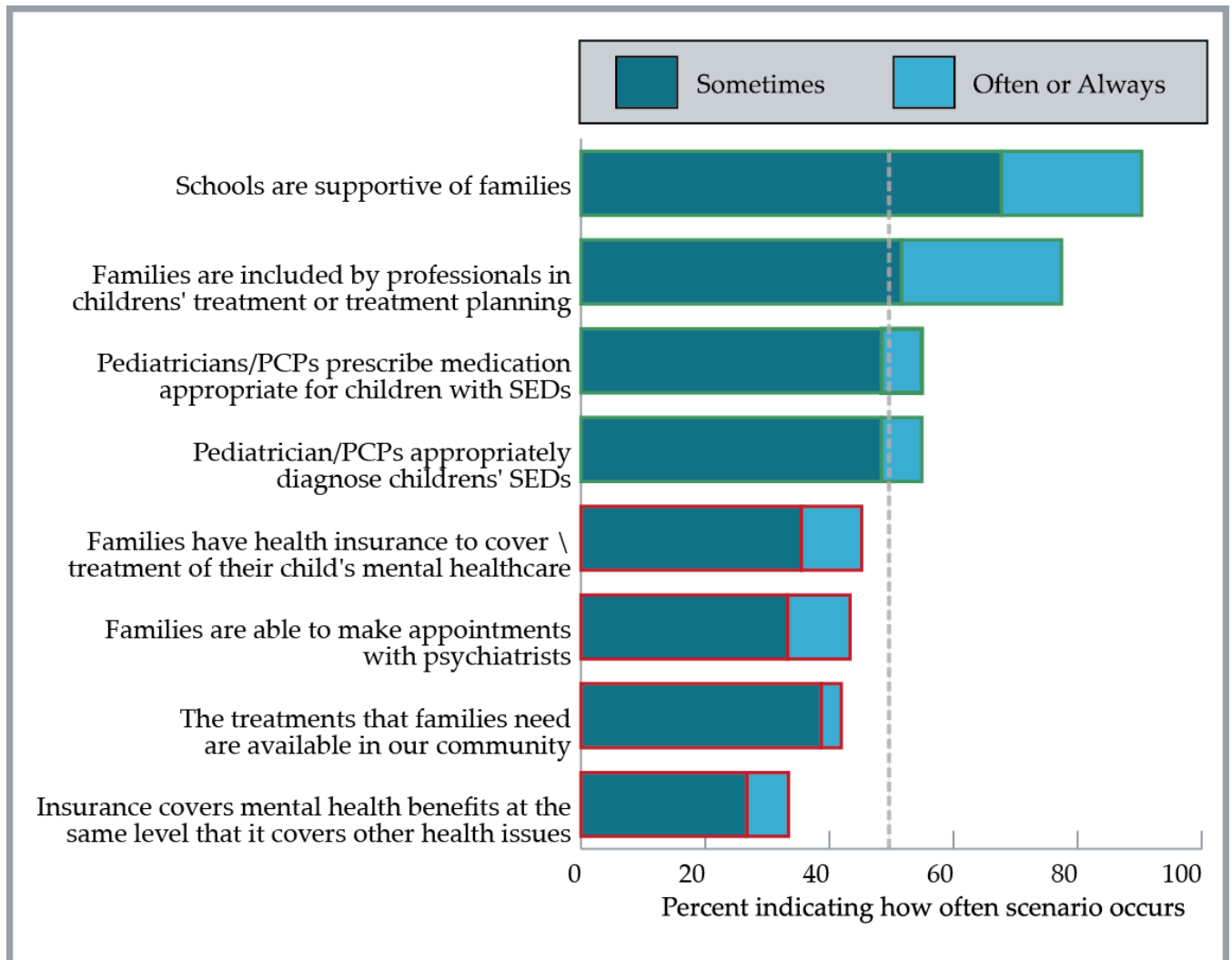
Figure 9. Negative scenarios occurring ‘often or always’



- ◆ 68% indicated schools do not have enough resources to provide support
- ◆ 81% indicated families struggle to understand health insurance coverage
- ◆ 90% reported that treatment options are limited by family income
- ◆ 94% indicated that children with SEDs often or always get labeled as “bad”

Stakeholders were also asked to rate the occurrence of eight scenarios that positively impact outcomes of children with SEDs (listed in Figure 10 below). The percent of respondents indicating a scenario occurs “sometimes” is shaded turquoise while the percent indicating a scenario occurred “often or always” is shaded pale blue. Scenarios identified as occurring “sometimes” or “often or always” by at least 50% of respondents are outlined in green and included schools being supportive of families, families being included in care, and pediatricians/primary care doctors appropriately diagnosing and prescribing medications. However, most respondents indicated these scenarios occur “sometimes” rather than “often or always”. In the remaining four scenarios, less than 50% of respondents indicated the scenario occurred at least “sometimes”. These four scenarios are outlined in red and demonstrate a need for available and covered mental health services.

Figure 10. Positive scenarios occurring “sometimes” and “often or always”



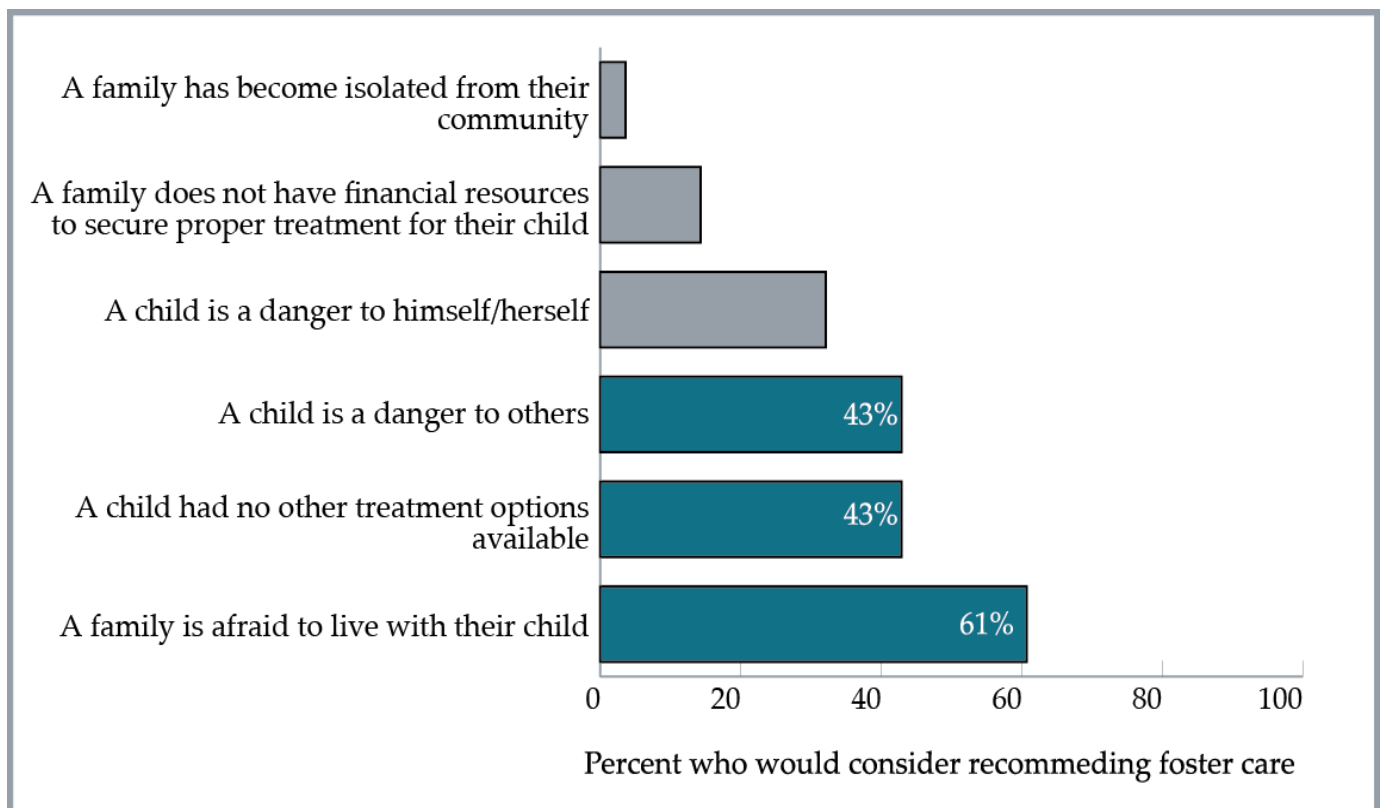
Child relinquishment

Stakeholders were asked if they had ever discussed with a family the possibility of a child going into foster care in order for that child to receive mental health treatment. Out of the 31 stakeholders who responded, 11 indicated “yes”. When asked specifically how many families they had recommended relinquishing care to a family to obtain mental health treatment for a child with a serious emotional disturbance, responses ranged from 1 to 20 families with the average being approximately 7 families.

Stakeholders that had recommended foster care were also asked whether they thought foster care was the best option. Half of these respondents reported that it was the best option at least for some of the families due to the lack of treatment options available to the family and/or the child’s level of safety in his or her environment. The remaining half of stakeholders who had discussed foster care with families believed it was rarely or never the best option for a family. They reported that these children are worse off when removed from their families; however, due to lack of treatment options, safety concerns, abuse, and/or family resources, foster care seemed like the only option.

All stakeholders were asked to review a list of scenarios that families of children with SEDs often face. From the list, stakeholders were asked to identify which scenarios they felt foster care would be considered a reasonable option for a child. Findings are presented in Figure 11 below.

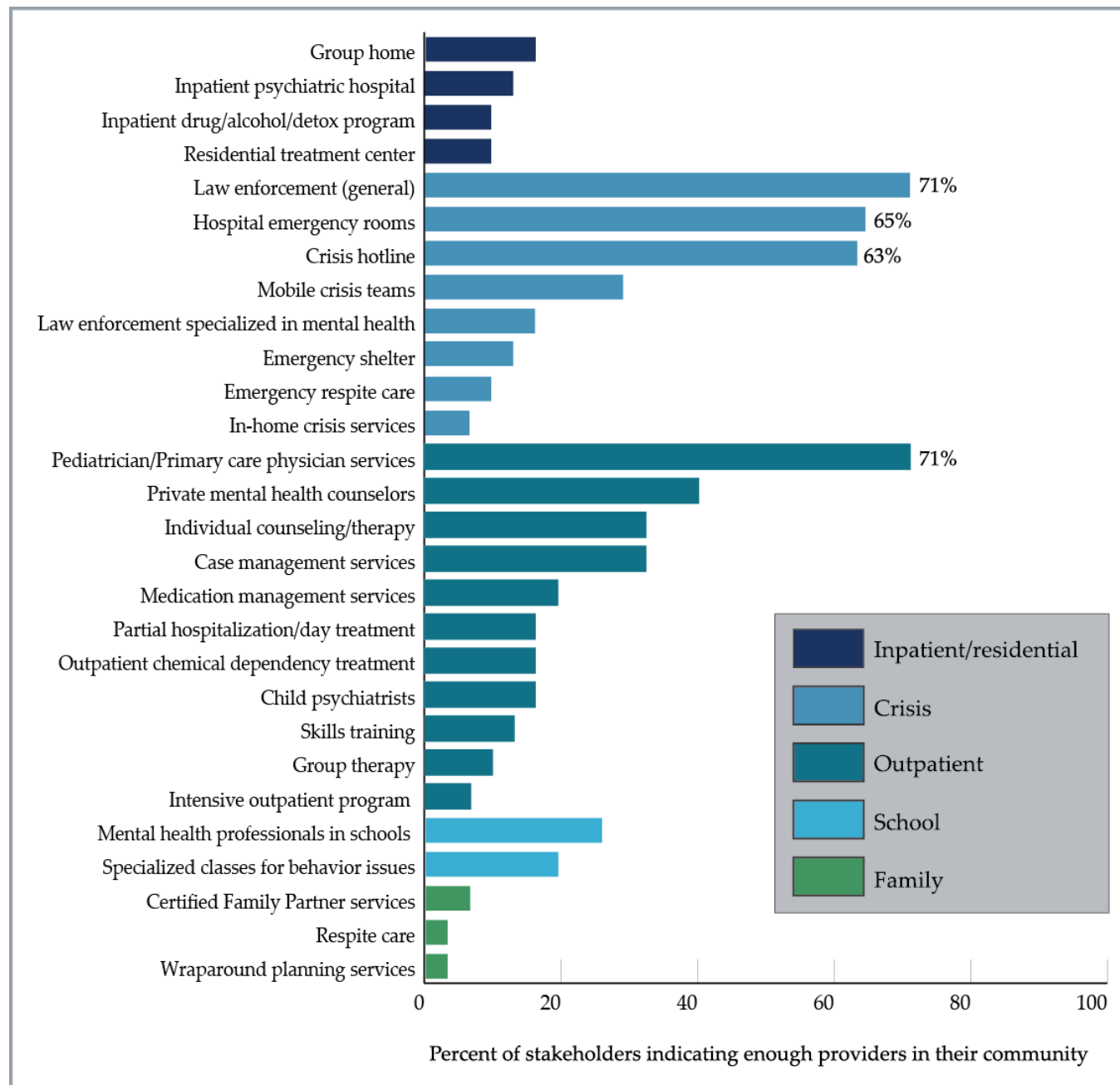
Figure 11: Scenarios where foster care may be considered a reasonable option



Provision of services

Stakeholders were provided with a list of 28 services intended for or used by families of children with SEDs. Service types included inpatient/residential services, crisis services, outpatient services, school services, and family services. For each service, stakeholders were asked to indicate whether or not there were enough providers in their area. Law enforcement (general), pediatricians/primary care physicians, hospital emergency rooms, and crisis hotlines were most commonly identified by stakeholders as services with enough providers. Figure 12 below provides a summary of findings.

Figure 12. Percentage indicating “enough providers in area” by service type



Service usefulness, affordability, and accessibility

Stakeholders rated services on usefulness, affordability, and accessibility using a three point Likert scale where 1 was equal to “not at all”, 2 was equal to “somewhat” and 3 was equal to “very much”. The average or mean score on usefulness, affordability, and accessibility was calculated for each service. Table 15 below lists all services in order from most useful to least. Means scores and rating for service affordability and accessibility are provided in order to compare usefulness, affordability, and accessibility. For example, mental health professionals in schools ranked number one in terms of usefulness. This service was considered to be more affordable (mean=2.40) but slightly less accessible (mean=1.97). Refer to image on the right for an explanation of rating system.

Rating Guide	
Mean	Rating
1.00 - 1.49	●○○○
1.50 - 1.99	●●○○
2.00 - 2.49	●●●○
2.50 - 3.00	●●●●

Table 14. Service affordability and accessibility ranked by usefulness

Usefulness Ranking	Service	Affordable		Accessible	
		Mean	Rating	Mean	Rating
1	Mental health professionals in schools	2.40	●●●○	1.97	●●○○
2	Certified Family Partner services	1.89	●●○○	1.22	●○○○
3	Wraparound planning process	2.04	●●●○	1.25	●○○○
4	Child psychiatrists	1.40	●○○○	1.37	●○○○
5	Individual counseling/therapy	1.70	●●○○	1.87	●●○○
6	Respite care	1.35	●○○○	1.14	●○○○
7	Case management services	2.08	●●●○	1.61	●●○○
8	Skills training	1.64	●●○○	1.59	●●○○
9	Group therapy	1.68	●●○○	1.48	●○○○
10	Private mental health counselors	1.55	●●○○	1.70	●●○○
11	Medication management services	1.75	●●○○	1.55	●●○○
12	In-home crisis services	1.58	●●○○	1.28	●○○○
13	Specialized behavior classes	2.04	●●●○	1.68	●●○○
14	Mobile crisis teams	2.24	●●●○	1.85	●●○○
15	Intensive outpatient program	1.32	●○○○	1.26	●○○○
16	Emergency shelter	2.00	●●●○	1.37	●○○○
17	Residential treatment center	1.23	●○○○	1.25	●○○○
18	Partial hospitalization/day treatment	1.28	●○○○	1.36	●○○○
19	Law enforcement (mental health)	2.52	●●●●	1.86	●●○○
20	Crisis hotline	2.55	●●●●	2.34	●●●○
21	Emergency respite care	1.32	●○○○	1.20	●○○○
22	Pediatrician/Primary care physician	1.86	●●○○	2.03	●●●○
23	Group home	1.39	●○○○	1.31	●○○○
24	Outpatient chemical dependency treatment	1.44	●○○○	1.33	●○○○
25	Inpatient drug/alcohol/detox program	1.23	●○○○	1.48	●○○○
26	Inpatient psychiatric hospital	1.41	●○○○	1.84	●●○○
27	Law enforcement (general)	2.52	●●●●	2.26	●●●○
28	Hospital emergency rooms	1.36	●○○○	2.42	●●●○

Findings suggest that accessible services are not generally considered to be the most useful services. For example, hospital emergency rooms, general law enforcement, pediatricians, and crisis hotlines were the top rated accessible services; however, in terms of usefulness, these services were all ranked in the bottom third. Crisis hotlines, general law enforcement, and law enforcement specialized in mental health were rated as the most affordable services. Again, these services were not considered as useful as others. Out of the top ten useful services, three were rated somewhat more affordable: mental health professionals in schools (mean=2.4), wraparound planning process (2.04), and case management (2.08). In general, a need exists to make useful services like mental health professionals in schools, Certified Family Partner services, and Wraparound Planning services more accessible and affordable to families of children with SEDs.

APPENDIX F: STAKEHOLDER INTERVIEWS

Methodology

Interviews were conducted with community stakeholders who represent the variety of service providers and systems that interface with families. Qualitative data was analyzed using conventional content analysis. A total of ten stakeholders were interviewed. Stakeholders included pediatricians, mental health policy associates, advocacy agencies, mental health policy analysts, researchers, psychologists, and psychiatrists. Each interview was conducted by a licensed social worker trained in data collection and research methods. Each interview was approximately one hour in length and interviews were conducted either in person or via phone. Interviewers followed a semi-structured interview guide and took notes throughout the interview.

Interview Guide

10. What is your understanding of SB 44?
11. What is your experience working with families who have a child with a serious emotional disturbance?
12. How do families utilize the following services for a child with a serious emotional disturbance?
 - Treatment from doctors, counselors, or therapists
 - Outpatient and intensive outpatient
 - Emergency and inpatient psychiatric treatment
 - Medication
 - Specialized programs or support at school
 - Juvenile justice or law enforcement
 - Availability of community support and resources
13. What services are most utilized in your community? Why?
14. What services do you feel your community is most in need of? Why?
15. What barriers do families face in utilizing services for a child with a serious emotional disturbance?
16. Have you discussed with or are you aware of families relinquishing care?
17. What support and resources do families need the most?
18. What policies are needed to support families?

Seven themes emerged in the interviews. These include: shortage of services, the YES program, inconsistent services, service expansion, mental health stigma, families as perpetrators, and relinquishment as a last resort. Together these themes capture the community stakeholder perspective on service provision, needed support, and the role of relinquishment.

Theme 1: Shortage of Services

All ten stakeholders described a shortage of services for children and families. The most frequently cited shortage was in areas of inpatient mental health care, psychiatric evaluations, and residential treatment. Participants also reported a severe shortage of child and adolescent psychiatrists. This shortage has resulted in families inappropriately relying on pediatricians for complex mental health care. One stakeholder reported that in their area of service, a child can wait up to two years just to get the testing necessary to get an accurate diagnosis.

Reasons cited for the lack of services include: provider shortages and lack of adequate funding through both private insurance and Medicaid. Stakeholders reported that the lack of adequate services creates a system in which parents must wait and react to crises because they do not have the services available to prevent the crisis.

Theme 2: The YES program

Stakeholders shared that the YES program is working. Despite the positive feedback, limitations to the program were noted. The limitation reported was that the program is not able to service enough families and does not have access to adequate residential treatment centers. Expansion of the YES program was the most frequently cited service that stakeholders felt their community was in needed.

Theme 3: Inconsistent Services

Stakeholders addressed the inconsistent services available through schools, law enforcement, and community resources. The most frequently discussed services were school and juvenile justice programs. Stakeholders reported a dearth of other community resources.

Participants cited a substantial variability in the services provided by school districts with some being helpful and others harmful to children. Several stakeholders used the term “re-traumatize” when describing the experience of children with serious emotional disturbance within school settings. In some school settings children with serious emotional disturbance face suspensions, expulsion, and placement in alternative high schools. It was reported that school personnel and teachers lack adequate training to work with children who have a serious emotional disturbance. Schools may call the police in response to a child’s behavior instead of utilizing less invasive treatments. Additionally, stakeholders shared the concern that the assessment and certification process for getting a child special education services can be extraordinarily long, delaying receipt of services.

Similar to school, stakeholders discussed the variability in juvenile justice services based on locality. Stakeholders describe juvenile justice as a catchment for children with serious emotional disturbance. They report that contacting law enforcement may be the only option for parents who cannot get services for their child. One stakeholder described juvenile justice as “a mental health emergency room.” Participants reported that children in need of community mental health services are frequently unable to get the services they need in a timely manner and as a result become involved in the juvenile justice system.

Theme 4: Service Expansion

Stakeholders reported that the children and families in their community are in need of additional services. Expansion of the YES program was most frequently identified as a needed service. Additional service needs included: emergency respite care, expansion of the CRCG model, wraparound services with intensive case management, psychiatric hospitalization, day treatment, residential services, and intensive outpatient treatment.

Participants discussed the importance of collaboration and shared responsibility among agencies. One participant suggested modeling the organization CRCG's after Community Advocacy Centers. Another stakeholder stressed the importance of including all community stakeholders: local mental health, child protection, schools, families, juvenile justice, and Medicaid and insurance providers.

Stakeholders also discussed financial challenges to the expansion of needed services. One stakeholder discussed the issue of the high cost of mental health services and the low reimbursement rates. The participant pointed out that even when expensive services like residential treatment centers are available, they are not staffed adequately due to the high cost. Another participant discussed the need for the use of Title IV-E funds and for Medicaid reimbursement for wraparound services. Finally, one stakeholder addressed the needs of children who are adopted but find themselves back in foster care. This participant pointed out the need for ongoing post adoption services to support the child and family and avoid adoption disruption.

Theme 5: Mental Health Stigma

Stakeholders discussed the disparity in the provision of mental health services versus other services such as those for children with developmental disabilities. One stakeholder shared that parents are forced to give up custody of a child with serious emotional disturbance to get treatment while parents who have a child with a disability can get services without judgment and without relinquishing their rights.

Theme 6: Families as Perpetrators

Stakeholders discussed how in the current system parents who are seeking treatment for a child with a serious emotional disturbance have the negative experience of being classified as a perpetrator in the child welfare system. One stakeholder reported that parents feel like "monsters" for experiencing feelings of relief when their child receives services following relinquishment. Parents who relinquish are placed on the child abuse registry which has both an emotional impact and affects employment for some parents.

Theme 7: Relinquishment as a Last Resort

Stakeholders reported that relinquishment is a last resort for families. Families have sought treatment and have been unable to receive the needed treatment. One stakeholder discussed the confusion of being a child protective services investigator and investigating parents who just need services. Stakeholders reported that families frequently discuss relinquishment because they are desperate to get their child services. Despite the desire for treatment, parents are aware of the challenges of relinquishment and worry about its impact on their child. One stakeholder shared the story of a mother who refused to sign over rights because of her fear that her son would think she abandoned him. The mother asked for joint conservatorship but was told that was not a possibility.

APPENDIX G: COST ANALYSIS

A cost-benefit analysis was conducted to examine the costs related to caring for a youth in foster care versus caring for a youth in the community. We begin this section by first summarizing the primary question of interest in terms of which costs more: placing a child with serious emotional disturbance in foster care or caring for a child with serious emotional disturbance in the community? Next, foster care placement costs related to relinquishment are addressed. The specific methods for cost calculations and relevant details are provided.

Which costs more: relinquishment or community care?

Caring for children with serious emotional disturbance is expensive. However, the care for children with serious emotional disturbance in the foster care system is most costly. It is estimated to cost \$93,661 annually to pay for the placement for a child with serious emotional disturbance within the foster care system. This amount does not include the cost of Medicaid for the child and administrative costs which will vary per child. In contrast, caring for a child with serious emotional disturbance in the community is estimated to cost \$30,420 annually. Thus, community care results in annual cost savings of \$63,241 per child with serious emotional disturbance.

Figure 13. Taxpayer costs of caring for a child with serious emotional disturbance



How much could DFPS save by having care provided to children with serious emotional disturbance in the community?

DFPS estimates that 107 children were in foster care in FY2011 and FY2012 because their caregivers relinquished custody in order to obtain mental health services for them. Assuming that all 107 children stayed in substitute care for a year, that all children were in care at the same time and utilizing the intense residential treatment rate of \$260.17 per day, it is estimated that DFPS would spend \$9,799,042 annually to provide substitute care placements to these children. In contrast, services in the community cost \$30,420 per child per year. If 107 children with serious emotional disturbance were being served in the community, it would cost \$3,254,940 per year resulting in a cost savings of \$6,544,102.

Figure 14. Estimated DFPS costs of caring for child with serious emotional disturbance



Cost benefit analysis methods

In 2011, The Children's Coordinated Funding Committee was charged with examining the fragmented funding and service coordination for children with serious emotional disturbance. The report by the Committee was developed by Drs. Manser and Lopez from the Institute for Mental Health Excellence at The University of Texas at Austin with federal funds from the Substance Abuse and Mental Health Services Administration (SAMHSA grant 5U79SMO57485-05). The very comprehensive report by the committee details the costs related to providing services to children with serious emotional disturbance. Additionally, in 2012, the Texas Institute for Mental Health Excellence conducted an evaluation of the Youth Empowerment Services (YES) Waiver Program on behalf of the Texas Department of State Health Services. Much of the data for this cost benefit analysis is derived from these reports.

Population estimate

It is estimated that 2% to 5% of all children have a serious emotional disturbance. In Texas, there are 6,829,733 children under the age of 18 (Census Bureau, 2010). Thus, there is a possibility that between 136,594 and 341,486 children in Texas may have a serious emotional disturbance. In order to calculate the potential foster care cost related to relinquishment, we utilized the mid-point between these numbers which is 239,040. As cited in our literature review, it is estimated that up to ¼ of children with serious emotional disturbance may be relinquished into foster care systems nationwide. In Texas, this would equate to a potential 59,760 children.

Foster care

Estimation of costs. The Department of Family and Protective Services has established daily provider reimbursement rates for children in foster care. This analysis used the 24-hour residential rates effective September 1, 2013. Reimbursement rates are determined by the service level of the child and the type of placement. Service levels are divided into the following categories: basic, moderate, specialized, and intense. According to DFPS descriptions of service levels, a child needing intense services most closely matches children with serious emotional disturbance. Thus, the rates for intense placements were used. There are multiple types of placements included for youth with intense service needs. Based on the interviews with families and stakeholders, placements in residential treatment centers are the most likely placements for youth with serious emotional disturbance. However, these youth are also likely to cycle between placements. For simplicity purposes, we used the intense residential treatment rates for to generate a cost estimate for caring for youth with serious emotional disturbance in foster care. The intense residential treatment facility rate is \$260.17 per day. We assumed 30 days in a month to determine a monthly rate. The estimated monthly cost for caring for 107 children with a serious emotional disturbance is \$835,145 (\$7,805 per child with serious emotional disturbance). These costs only reflect the cost of placement and do not reflect cost for Medicaid and/or DFPS administrative costs.

Identification of cases. SB44 cases meet the following fundamental criteria: children admitted into the CPS system as a result of the caregiver's inability to provide mental health services. Using this definition as a guide, CPS set out to obtain an accurate picture of how many SB44 cases the Department encountered over two recent fiscal years. The Department requested data on all children placed in substitute care during FY 2011 and FY 2012, AND whose first or second placement was in a psychiatric facility or a residential treatment center. Certain characteristics were also included in the request which included demographic information, reason for removal, service level, characteristics of the children, etc. This yielded 437 cases.

All 437 cases were read to find explicit evidence in the case record to unequivocally establish that the case was indeed admitted for services solely due to the caregiver's inability to provide mental health services. CPS readers found 107 SB44 cases (24.5% of the total) meeting this definition. In an effort to check the validity of the parameters we used to identify candidates for SB44 cases, we made some *a priori* hypotheses about which parameters would be most likely associated with SB44 cases. Table 16 lists our parameters in order of our estimates of greatest to least probability of indicating an SB44 case. The categories were mutually exclusive. Of the 107 cases which met the SB44 definition, 92.6% fell into one of the first 3 categories. None of the 107 cases fell into the catch-all "other" category. Because the vast majority of cases occurred within the top 3 identified categories, we are confident that the parameters we used to identify possible SB44 cases were reasonably exhaustive and produced an accurate estimate of the number of SB44 cases occurring from FYs 2011-2012.

Table 15. Number and percentage of cases by case criteria

Case Criteria*	Number of Cases - Total from Data Request	Number of SB44 Cases found ¹	Percent of SB44 Cases found
Removal Reason: Lack of MHMR Services	36	22	20.6%
Initial Placement in a Psychiatric Facility	183	51	47.7%
Removal Reason: RAPR ²	124	26	24.3%
Child ever Placed in Psychiatric Hospital	30	1	.9%
First ALOC (Authorized Level of Care) after removal either intense or specialized	48	7	6.5%
Other	16	0	0.0%
Total	437	107	100%

*These case criteria categories were constructed so that they were mutually exclusive. In reality, a child may fit multiple criteria.

¹ 30 of the identified SB44 cases occurred in the post adoption stage. The breakdown is as follows (9 with Removal Reason: Lack of MHMR services, 12 with an initial placement in a psychiatric facility, 7 with a removal reason of RAPR, 1 with child ever placed in a psychiatric hospital, and 1 with a first ALOC after removal either intense or specialized.

² RAPR - Refusal to Accept Parental Responsibility. In these cases the parents articulated to CPS that they were no longer willing to care for their child. Oftentimes in these cases parents will bring the child to CPS offices or refuse to pick the child up from a mental health facility or juvenile justice facility.

Community care

In order to compare the cost of caring for children with serious emotional disturbance to children in foster care, the YES Waiver Program is used as a comparison. The YES Waiver is described in more detail in the background section. Because the purpose of the YES waiver is to provide intensive community-based services to youth at risk of psychiatric treatment or relinquishment, the costs of this program offer an ideal comparison for what it costs to serve youth with serious emotional disturbance in the community

According to an evaluation of the YES Waiver, youth received services for an average of 234.4 days or roughly 7.8 months. Table 16 details the average costs per youth enrolled in the YES Waiver program. The total cost of providing the waiver program to 81 youth was \$905,350 or \$19,769 per child. Given that the average youth remains in the program for 7.8 months, the monthly cost per child is \$2,534.49.

Table 16. Costs of services for youth in YES waiver program

Services	Children served	Total cost	Cost per child
Traditional services provided by local mental health authority			
Screening or assessment	47	\$10,548	\$224.43
Benefit eligibility	10	\$714	\$71.40
Routine case management	6	\$695	\$115.83
Intensive case management (wraparound)	98	\$480,459	\$4,902.64
Medication services	34	\$15,887	\$467.26
Medication training	2	\$176	\$88.00
Skills training or rehabilitation	3	\$1,803	\$601.00
Counseling	23	\$57,618	\$2,505.13
Flexible funds	27	\$20,618	\$763.63
Crisis services	27	\$21,759	\$805.89
YES Waiver Services			
Community living services	81	\$81,150	\$1,001.85
Family support services	66	\$23,803	\$360.65
Professional services			
Nutritional counseling	26	\$18,007	\$692.58
Music therapy	17	\$14,012	\$824.24
Art therapy	13	\$14,796	\$1,138.15
Recreational therapy	37	\$97,019	\$2,622.14
Paraprofessional services	28	\$25,852	\$923.29
Respite	8	\$9,206	\$1,150.75
Adaptive Aids and Supports	22	\$11,228	\$510.36
TOTALS	103	\$905,350	\$19,769
*Data from the Youth Empowerment Program Services Program Evaluation file:///C:/Users/MonicaF/Downloads/YES_Evaluation_FullReport_Jan2013_040513.pdf			