SARASOTA COUNTY

Child and Youth Mental Health Environmental Scan

Final Report (7/16/18 – 2/28/19)

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Child and Youth Mental Health Environmental Scan

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Child and Youth Mental Health Environmental Scan

Executive Summary

This environmental scan of mental health services for children, youth, and young adults in Sarasota County encompasses multiple areas of inquiry, including the following: 1) a needs assessment, 2) a report card of current services, 3) a discussion of primary care providers' role in mental health, 4) an assessment of barriers and challenges, 5) a projection of the costs of untreated mental health, 6) an overview of national benchmarks, and 7) a strategic framework for making system improvements. Major findings from each of these sections are presented below.

Needs Assessment

The needs assessment compiles secondary data on Sarasota County population statistics as well as data on mental health needs compiled from various administrative and community databases. Analysis of these data points to the following areas of need:

- Prevention and community-based services
- Treatment for transition-aged youth
- Focus on family, youth, and young adult engagement in services
- Focus on increasing awareness of trauma

Report Card and National Benchmarks

Using the participatory process employed in the Community Health Improvement Plan, which is currently under review for the next planning cycle, Community Health Improvement Plan indicators should be expanded to address adults, young adults, and children and to include the following domains:

- Prevalence of mental health disorders
- Access to mental health care
- Perceptions of well-being as well as outcomes represented for both the child, young adults and adults

In addition, the use of the Health plan/Employer Data Information System (HEDIS) behavioral health measures is recommended because they are used broadly by public, i.e., Medicaid and Medicare, as well as private payers (National Committee for Quality Assurance, no date). These measures address effectiveness of care, access and availability of care, and utilization.

Barriers and Challenges

A significant amount of first-hand data was gathered to assess barriers and challenges from the community, including parents/caregivers with children in mental health services, youth, young adults, mental health stakeholders, and primary care providers. Some key findings from this data are presented below:

- Some of the services that are lacking in Sarasota County include inpatient care, residential treatment programs, independent living options for adults, case management, post-discharge services from crisis stabilization units, and youth psychiatric treatment.

- Prevention and early intervention services at the early childhood and elementary levels were missing from a comprehensive system of mental health care.
- Many barriers to access exist, including insurance and Medicaid coverage and usage, lack of awareness by parents of how to find and begin services, transportation access and lengthy commute times, time constraints for families during typical workday hours, and stigma.

Impact of Unmet Need

When mental health problems go untreated, there is a negative impact on quality of life of the child, adolescent, young adult, and family members, which extends into schools, workplaces, and social structures.

- It is estimated that the economic cost due to untreated mental illness for children and young adults in Sarasota County is $86,179,317 per year.
- The primary drivers of this cost are suicide, criminal justice, education, and worker productivity.

Strategic Framework

This report includes a suggested framework for making strategic improvements to mental health services for youth in Sarasota County based on the System of Care model. Below are the key recommendations for implementing systems change:

- Develop or identify an interagency governance structure for mental health policy, such as the Behavioral Health Stakeholders Consortium.
- Focus system entry points to allow for easier access of services by families by expand implementation of centralized intake system recommended in the 2017 SIM report to include children, youth and families in addition to adults.
- Implement standardized comprehensive trauma-informed screening and assessment protocols, continue Adverse Child Events training, and conduct a trauma – informed organizational and system assessments in concert with the Circuit 12 trauma – informed workgroup.
- Cultivate financing strategies and structures that improve system effectiveness using models applied elsewhere in Florida or expanding the Child Welfare Behavioral Health Integration report and toolkit.
- Develop quality assurance mechanisms and build cross – system data infrastructure for real – time care coordination and system management.
- Strengthen intensive care coordination for high need youth by implementing evidence-based practices such as Wraparound for high utilizers in the context of Master Case Management model used in the Homeless Response System.
- Increase family supports in direct services, such as Certified Peer Recovery Specialists, as well as ensuring meaningful representation and participation on governance boards in the community and among provider organizations.
- Enhance prevention and early intervention services including universal prevention in communities and neighborhoods, as well as targeted interventions for specific disorders and risk behaviors.
- Continue and expand training and professional development of law enforcement and school resource officers in Crisis Intervention Training, develop sustainability plans for school-based mental health professionals and attraction and retention of mental health professionals in Sarasota.

Introduction

This report details the findings for each of the evaluation objectives outlined in the request for proposals for an environmental scan of Sarasota County's mental health services for children, youth, and young adults. The report covers the period of July 16, 2018 through January 15, 2019. Findings are derived from both primary data collection and administrative data analysis, providing a comprehensive overview of the current array of mental health services for youth in Sarasota County, as well as, various community perspectives on the effectiveness of services and gaps in the system.

This evaluation is a culmination of several efforts in Sarasota County over the past two decades that have set the stage for a large-scale initiative for understanding and improving mental health care among children, youth, and young adults in the county. The 2003 Sarasota County Openly Plans for Excellence (SCOPE) report on mental health helped to define existing gaps in services at the time, including lack of coordination and communication among service providers, stigma of mental illness among the community, and the inadequate training of law enforcement for working with people experiencing mental health crises and initiating Baker Acts exams. One significant outcome of the SCOPE study was the establishment the group now known as the Behavioral Health Stakeholders Consortium, which is comprised of representatives from numerous human services and youth-serving organizations and continues to play an active role in influencing decisions about mental health services in the county. Additionally, community leaders have begun to address the gaps identified in the report through Senate Bill 12 (SB 12) (2016) requirements, including the development a "No Wrong Door" policy, the creation of a Centralized Receiving System, and the establishment of a shared data system among providers and the Managing Entity. The existing Sarasota County Transportation plan was enhanced pursuant SB 12 and specifies procedures for transporting children under Baker Act, and Crisis Intervention Training (CIT) has been implemented with law enforcement and school resource officers. Other initiatives include an expanded Mobile Crisis Response Team, a Student Assistance Program in all high schools, and the development of inter-agency meetings and conferences that address children and youth's mental health needs.

A five-year Health Improvement Plan (2015 – 2020) was released in 2017 by the Florida Department of Health (DOH) in Sarasota County, in which improvement goals were identified specifically around improving access to mental health services. Simultaneously in 2017, the Florida Policy Institute reported that Florida's per capita support for mental health services ranks last among all the states, indicating a significant need to address barriers to mental health care. The Sarasota County DOH is currently in the early stages of conducting a Community Health Assessment during 2019, and community feedback is being sought to help identify priority areas for health improvement. These efforts speak to the readiness of Sarasota County community leaders to move into a more strategic direction for making improvements in the county's mental health services. The environmental scan conducted by the University of South Florida will help inform process and provide a concrete strategic framework for carrying out the vision of having a robust system of mental health care in the county.

The problems that occur when mental health systems are inadequate for a community's needs are grave, and many of these challenges have been highlighted by recent reports in local and national media. Emergency rooms become flooded with patients who are unable to find appropriate mental health care (Scutti, 2019), schools are ill-equipped to meet the needs of students with unassessed mental health needs (Von der Embse, 2018), and parents become frustrated and feel helpless when appropriate pediatric mental health specialists are few and far between (Spiezle & Goldy, 2018). There is recognition by many that Florida, with some of the lowest funding nationwide for mental health, needs to invest more in its mental health care systems

(South Florida Sun Sentinel, 2019). The growing awareness of the impact of mental health inadequacies is encouraging, and there are many opportunities for improving systems based on this widespread drive to enact change.

In this report, findings for each of the six objectives for the Environmental Scan are shared, with data on existing indicators of mental health care for youth in Sarasota County as well as perspectives on strengths and opportunities in the system. In the final section, a Strategic Framework is presented with recommendations for making system improvements unique to the barriers, challenges, and resources of Sarasota County.

Objective 1: Needs Assessment

Sarasota County Description

The purpose of this assessment was to describe Sarasota County in terms of its demographics, especially of the population of focus, and to identify risk and protective factors in the community using publicly available data.

This scan and needs assessment was conducted for Sarasota County, Florida. The county was incorporated in 1921 and is located along the west coast of Florida. It covers 725 square miles and includes 37 miles of coastline on the Gulf of Mexico. Sarasota County's 2016 population was 399,238 (see Table 1) (Source: 2016 Demographic Profile: US Census Bureau). Sarasota County is located on the west coast of Florida in the North Port - Sarasota - Bradenton Metropolitan Statistical Area (MSA) and includes the cities and towns of Sarasota, Venice, Longboat Key, and North Port, with Sarasota serving as the county seat (Sarasota County Government, no date). It was the 14th most populous county in Florida at the end of 2018 (Economic and Demographic Research Bureau (EDR)) but ranked 64th in the proportion of the population under 18.

Table 1: Population and Growth

Year	Population	Number change	Percent change
2010	379,448	-9872	-2.5
2011	381,319	1871	0.5
2012	383,664	2345	0.6
2013	385,292	1628	0.4
2014	387,140	1848	0.5
2015	392,090	4950	1.3
2016	399,538	7448	1.9
2017	407,260	7722	1.9

Source: KIDS Count Data Center

Method

Secondary data sources were used to provide a description of Sarasota County and its residents. In addition to demographic characteristics of children, youth, and families, data are presented on risk factors and trauma that have an impact on mental well-being.

The Population of Sarasota County

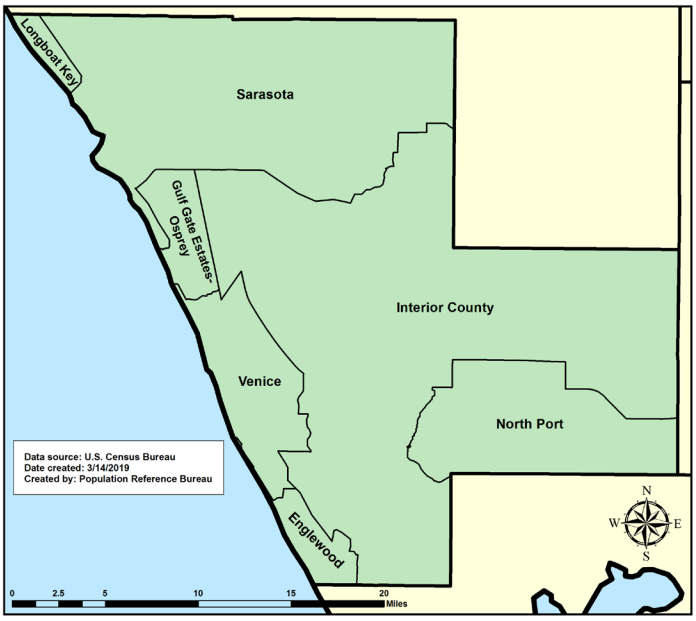
The population for Sarasota County at the time of the census in 2010 was 379,495 and has been increasing steadily over time and reached 399,538 in 2016 (see Table 1). The county's population increased 5.9% between 2010 and 2016. It is anticipated to increase by 2.1% by 2020 and 6.5% by 2025 to a population of 454,226 (EDR, 2018).

Child, Youth, and Young Adult Population of Sarasota County

Roughly 15% of Sarasota County's residents are under 18 years of age (14.9% N = 60,488) and 20.0% are under the age of 25 (N = 82,709). For children under 18, the population is expected to reach 66,427 and for those 18-24 years of age, it is expected to reach 25,808 by 2025, a change of 9.8% and 3.9% respectively. In sum, there has been small to modest growth in population since 2011 and this growth will continue.

With respect to geographic distribution, Sarasota has seven Census County Divisions (CCDs): Englewood, Gulfgate Estates – Osprey, Interior County, Longboat Key, North Port, Sarasota, and Venice. The highest proportion of residents under 25 live in the North Port, Sarasota and Venice CCDs (ACS, 2017). Table 2 shows the population by Race and Hispanic/Latino Origin.

Map 1: Sarasota County Census County Divisions (CCDs)



Sarasota County Births

In 2017, there were 2,819 total births, a birth rate of 6.9 per 1,000 which is lower than the state birth rate of 10.9 per 1,000 in the same period. There were 120 births to mothers under the age of 20, including 17 repeat births to mothers ages 15-19. There were 1,031 births to mothers who were eligible for Women, Infant, and Children's (WIC) Nutrition Program services, and 41.8% (N=1,178) of births were paid for with Medicaid. Medicaid and WIC eligibility is a commonly used proxy measure for low socioeconomic status which may affect the health and developmental needs of these babies. The highest proportion of such births were to mothers in the 34234 (North Sarasota, N=131), 34232 (Sarasota Springs/Fruitville, N=68), and 34287 (North Port, N=74) zip codes.

The 2015-17 three-year estimate of the number of WIC eligible served was 22,954, a rate of 68.8 which is significantly lower than the state rate of 72.1 (CHARTS, 2017).

In 2017, there were 215 births to Sarasota County mothers without a high school diploma. Sarasota's County's 2017 rate of 7.6% was lower than the state rate of 12.0%. The zip codes with the three highest numbers of such births was 34234 (North Sarasota, N=48), 34232 (Sarasota Springs / Fruitville, N=26) and 34237 (Sarasota, N=23). Births to mothers without a high school diploma have been on a slow but steady decline from 19.3% in 2006-2008 to 8.4% in 2015-17 (CHARTS, 2017).

Low Birthweight Babies

Another indicator of need for better prenatal care and nutrition is the proportion of low birthweight babies. Low birthweight is also a proxy for prematurity and disproportionately effects mothers and children of color (Florida KIDS COUNT, 2018). In Florida, low birthweight is defined as 2500 grams or roughly five and a half pounds, and the state ranks 35th nationwide with 8.7% of live births being born at low birthweights in 2018 (Americashealthrankings.org). The zip codes with the highest proportion of low birthweight babies were 34234 (North Sarasota, N=34), 34231 (South Gate Ridge/ South Sarasota, N=17) and 34232 (Sarasota Springs / Fruitville, N=17).

According to the State Department of Health, teen mothers are more likely to drop out of high school than girls who delay childbearing. With lower education achievement, teen mothers also have lower incomes than peers who delay pregnancy. A child born to an unmarried teenage

mother is more likely to become incarcerated, is at risk of poor educational outcomes and to themselves become teen mothers (CDC, No date).

Overall, in Sarasota County, as in Florida more generally, the rate of teen births has been slowly but steadily declining since 2006-2008 to a current rate of 4.5 for mothers 0-19 years of age. This is significantly lower than the state rate of 5.1.

Immunizations

Among two-year-olds, 79.9% were fully immunized, which is lower than the statewide rate of 86.1% in 2017. In 2018, 2,874 Kindergarten students were up to date on their immunizations or 90.0%, below the state average of 93.7%

Infant Deaths 2015-2017

There were 15 infant deaths reported in Sarasota County in 2017. The most common reasons were congenital malformations and unintended injury.

Households and Families

According to the 2017 American Community Survey, Sarasota County had 177,998 households, of which 108,183 were family households. Families made up 63.5% percent of the households in Sarasota County and included an average of 2.8 household members. This figure includes 81.1% married-couple families (N=87,701), 5.0% male householder families (no wife present) (N=5,444), and 13.9% female household families (no husband present) (N=15,038). Non-family households made up 39.2% of all households in Sarasota County. Most of the non-family households were people living alone (83.6%), but some were composed of people living in households in which no one was related to the householder.

Of the total family households with children (N=27,288), male householder families (no wife present) was 7.4%, married couple family households with children accounted for 66.8% of households with children, and female headed household with children 25.7% of households with children.

Nativity and Language

In 2017, 85.9% of Sarasota County residents were born in the US, its territories and commonwealths or to American parents living abroad. Most of the population speaks English only (87.1%). Among those who speak languages other than English, Spanish was most commonly spoken (53.1%, N=26,686), with other Indo-European languages (35.7%) and Asian Pacific Islander languages making up the third largest group (7.4%).

Race and Ethnicity

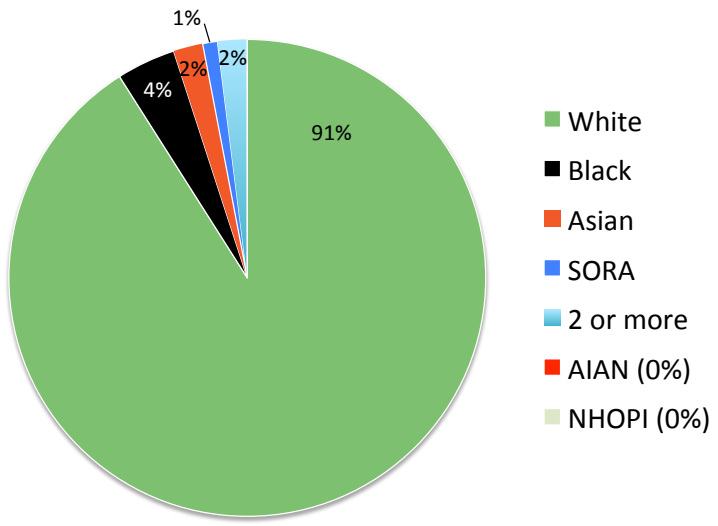
With respect to the demographic make-up of Sarasota's residents, for people reporting one race alone, 91.3% identified themselves as White; 4.5% were Black or African American, 1.7% identified as Asian, 1.0% reported being Native Hawaiian or Pacific Islander, American Indian and Alaska Native, or other single race alone, and 1.6% percent identified as belonging to two or more races (see Table 2 and Figure 1). Among children under five, 82.5% were White, 7.9% identified themselves as African – American or Black, 3.3% identified as being from another race, and 6.3% identified as belonging to two or more races.

Table 2: Population by Race and Hispanic/Latino Origin, 2017

	Total Population	White	Black or African American	Other and two or more races	Hispanic Population (of any race)	Hispanic/ Latino	Not Hispanic /Latino
Florida	20,278,447	15,343,997	3,270,863	1,663,587	5,015,015	24.7	75.3
Sarasota County	404,839	369,537	18,338	16,964	35,694	8.8	91.2
Engelwood, CCD	11,767	11,327	37	403	473	4	96
Gulfgate Estates-Osprey, CCD	28,636	27,587	88	961	2,412	8.4	91.6
Interior County, CCD	34,944	33,680	79	1,185	1,253	3.6	96.4
Longboat Key, CCD	4,653	4,519	0	134	147	3.2	96.8
North Port, CCD	67,023	58,399	5,399	3,225	4,483	6.7	93.3
Sarasota, CCD	188,624	168,155	11,898	8,571	24,717	13.1	86.9
Venice, CCD	69,192	65,870	837	2,485	2,209	3.2	96.8

Source: ACS B03001

Figure 1. Race within Sarasota County, 2017



Source: ACS 2013-2017 5 year estimates B01001

8.8% of the people in Sarasota County identified themselves as Hispanic or Latino. The areas with the highest proportions of residents identifying as Hispanic or Latino lived in Sarasota CCD (13.1%), Gulfgate Estates-Osprey CCD (8.4%) and North Port (6.7%). Countywide, 19.2% of children under 18 identified as Hispanic (see Tables 3 and 4).

Table 3: Hispanic / Latino by Country of Origin, 2013-2017

		Total Population	Not Hispanic or Latino	Hispanic or Latino	Mexican	Puerto Rican	Cuban	Dominican (Dominican Republic)	Central American	South American	Other Hispanic or Latino
Florida	N	20,278,447	15,263,432	5,015,015	694,779	1,065,351	1,450,510	221,858	540,978	865,161	176,378
	%		75.3	24.7	13.9	21.2	28.9	4.4	10.8	17.3	3.5
Sarasota County	N	404,839	369,145	35,694	11,649	6,415	6,059	1,106	2,542	6,420	1,503
	%		91.2	8.8	32.6	18.0	17.0	3.1	7.1	18.0	4.2
Engelwood, CCD	N	11,767	11,294	473	247	53	6	0	0	117	50
	%		96.0	4.0	52.2	11.2	1.3	0.0	0.0	24.7	10.6
Gulfgate Estates-Osprey, CCD	N	28,636	26,224	2,412	365	389	428	242	102	615	271
	%		91.6	8.4	15.1	16.1	17.7	10.0	4.2	25.5	11.2
Interior County, CCD	N	34,944	33,691	1,253	246	234	272	53	140	81	227
	%		96.4	3.6	19.6	18.7	21.7	4.2	11.2	6.5	18.1
Longboat Key, CCD	N	4,653	4,506	147	0	0	19	0	9	108	11
	%		96.8	3.2	0.0	0.0	12.9	0.0	6.1	73.5	7.5
North Port, CCD	N	67,023	62,540	4,483	1,416	1,866	190	20	129	744	118
	%		93.3	6.7	31.6	41.6	4.2	0.4	2.9	16.6	2.6
Sarasota, CCD	N	188,624	163,907	24,717	8,858	3,375	4,724	773	2,039	4,278	670
	%		86.9	13.1	35.8	13.7	19.1	3.1	8.2	17.3	2.7
Venice, CCD	N	69,192	66,983	2,209	517	498	420	18	123	477	156
	%		96.8	3.2	23.4	22.5	19.0	0.8	5.6	21.6	7.1

Source: ACS 2013-2017 5-year estimates B03001

Table 4: Sarasota County Children under Age 18 and Age 18-24 by Race and Hispanic/Latino Origin

		2013	2014	2015	2016	2017	Percent Change 2013-2017
White non-Hispanic	Age <18	41,360	40,331	40,817	41,079	41,386	0.1
	Age 18-24	17,794	18,010	73,571	17,397	17,274	-2.9
Black or African American non-Hispanic	Age <18	5,523	5,542	5,682	5,730	5,802	5.1
	Age 18-24	1,998	2,077	2,112	2,109	2,111	5.7
Other Race Alone or Two or More Races non-Hispanic	Age <18	1,490	1,519	1,579	1,616	1,659	11.3
	Age 18-24	502	533	550	560	572	13.9
Hispanic	Age <18	10,416	10,699	10,782	11,255	11,641	11.8
	Age 18-24	3,865	4,012	4,924	4,597	4,871	26.0

Data Source: EDR

Table 5 shows Sarasota County's current estimates and population projections by race and ethnicity. For the county as a whole, children under 18 constitute 14.9% of the county's population and is growing at a slightly higher rate than the County population overall. When examined by race and ethnicity however, Black children are anticipated to grow at a slightly faster rate and Hispanic children are expected to grow at a much faster rate. In Sarasota schools, the majority of students are White (63.1%), with African Americans comprising 8.5% of students and Hispanic / Latinos making up the third largest group (20.1%).

Table 5: Sarasota County Total Population, Under Age 18 and Age 18-24

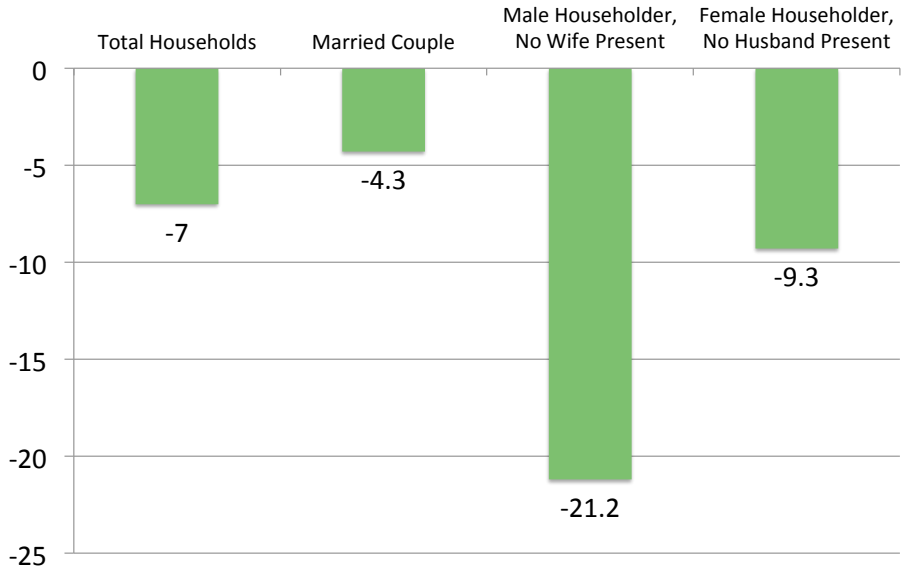
		2017	2025	2035	Percent Change 2017-2035
White non-Hispanic	Age <18	41,386	43,191	46,273	11.8
	Age 18-24	17,274	15,982	16,549	-4.2
	All Ages	340,033	366,705	387,938	14.1
Black or African American non-Hispanic	Age <18	5,802	6,496	7,146	23.2
	Age 18-24	2,111	2,145	2,340	10.8
	All Ages	20,148	23,989	27,452	36.3
Hispanic	Age <18	11,641	14,676	17,528	50.6
	Age 18-24	4,871	7,014	7,473	53.4
	All Ages	40,182	55,351	69,140	72.1
All Races	Age <18	60,488	66,427	73,366	21.3
	Age 18-24	24,828	25,808	27,155	9.4
	All Ages	407,260	454,226	439,851	8.0

Source: EDR

Household Characteristics

Figure 2 shows the change that has occurred from 2012 to 2017 for each type of household. All households with children under age 18 showed a decrease with male heads of household without a wife present showing the largest decrease.

Figure 2. Change in Household Characteristics, Sarasota County, 2012-2017



Source: ACS S1101

Education

Sarasota County Public Schools is the 19th largest district in Florida with 42,901 pre-kindergarten through senior high students in school year 2017-18. In school year 2017-18, there were 24 elementary, 7 middle, and 5 senior high schools. There are also 11 charter schools that serve multiple grades as well as alternative education, exceptional student education, pre-school, and schools categorized as special, which includes enrollment in Florida virtual school.

Sarasota County also has several universities and colleges. The University of South Florida – Sarasota - Manatee serves 2,041 students. New College, Florida's designated Honors College, serves 809 undergraduates and 29 graduate students. State College of Florida, Manatee –

Sarasota, is another undergraduate option in the Sarasota community and has three campus locations in Bradenton, Lakewood Ranch, and Venice, plus a virtual option. Other options and specialized programs include Keiser University, Ringling College of Art and Design, Webster, Argosy, Eckerd College and FSU College of Medicine.

The 2007-2011 American Community Survey 5-Year Estimates – Selected Social Characteristics in the United States identified 87.3% of people 25 years and over had at least graduated from high school and 29.8% percent had a bachelor's degree or higher.

Disability

In Sarasota County, 12,041 students had disabilities as identified by the school district. 202 have emotional or behavioral disabilities (1.7%) and 548 were on the Autism Spectrum (4.6%).

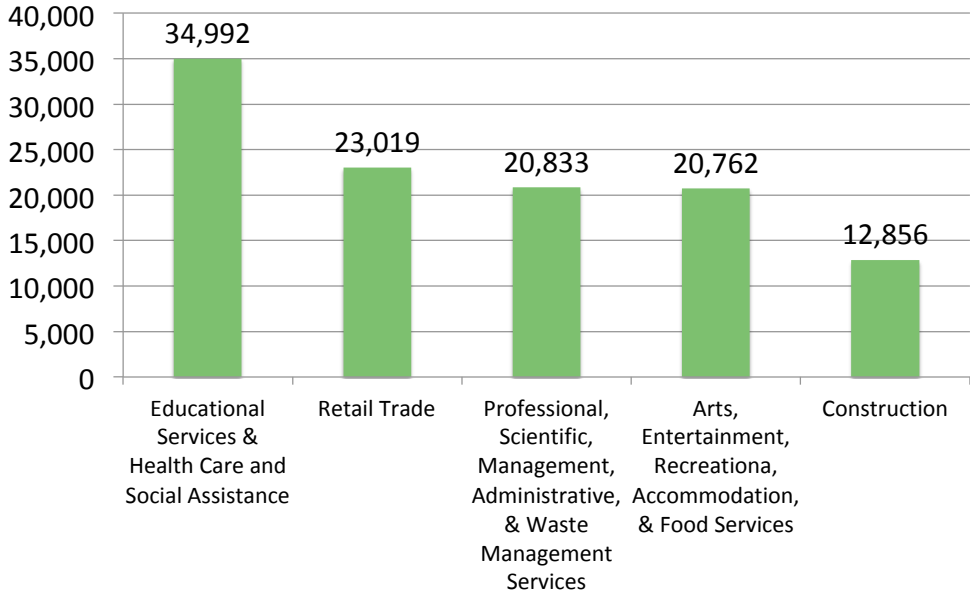
Employment

Occupations, industries and type of employer. According to the 2013-2017 American Community Survey, among the population aged 16 years and older, 43.6% were in the labor force.

The five most common employment categories in Sarasota County are educational services (21. 8%), retail (14.4%), arts and entertainment (13.0%), professional and scientific (13.0%), and construction (8.0) (see Figure 3). According to the Tampa Bay Business Journal, the County's five largest employers include the School District of Manatee County, Sarasota Memorial Health Care System, Sarasota County School District, Beall's Inc., and Sarasota County Government.

Figure 3. Employment by Industry for the Civilian Employed Population 16 Years and Over (2017)

Source: ACS C24050



Employment rate. The Bureau of Labor Statistics identified the unemployment rate for Sarasota County as 4.8% in 2018 (Florida KIDS COUNT, 2018).

Poverty and participation in government programs

Poverty. The child poverty rate in Sarasota County is 17.9% and decreased between 2011 and 2016. Children are more likely to be poor in families with a single-parent female head of household. Of Sarasota County's 108,183 families, 6,698 (6.2%) lived in poverty in 2017. Among these families 57.8% had minor children. Female heads of household living in poverty with no husband present represented 57.9% of all family households with related children under 18 living in poverty. See Table 6.

Table 6: Families by Type with Related Children under Age 18 Living below Poverty, 2017

	Number	Percent
Florida		
Total Families	4,847,306	
Families with income in the past 12 months below poverty level	539,921	
Families with related children under 18 years living below poverty level	371,528	68.8
Sarasota County		
Total Families	108,183	
Families with income in the past 12 months below poverty level	6,698	
Families with related children under 18 years living below poverty level	3,873	57.8
Engelwood, CCD		
Total Families	3,489	
Families with income in the past 12 months below poverty level	231	
Families with related children under 18 years living below poverty level	122	52.8
Gulfgate Estates-Osprey, CCD		
Total Families	8,147	
Families with income in the past 12 months below poverty level	416	
Families with related children under 18 years living below poverty level	177	42.5
Interior County, CCD		
Total Families	10,665	
Families with income in the past 12 months below poverty level	378	
Families with related children under 18 years living below poverty level	183	48.4
Longboat Key, CCD		
Total Families	1,711	
Families with income in the past 12 months below poverty level	28	
Families with related children under 18 years living below poverty level	0	0.0
North Port, CCD		
Total Families	17,473	
Families with income in the past 12 months below poverty level	1,154	
Families with related children under 18 years living below poverty level	762	66.0
Sarasota, CCD		
Total Families	46,768	
Families with income in the past 12 months below poverty level	3,540	
Families with related children under 18 years living below poverty level	2,266	64.0
Venice, CCD		
Total Families	19,930	
Families with income in the past 12 months below poverty level	951	
Families with related children under 18 years living below poverty level	363	38.2

Source: ACS B17010

The determination of poverty is based on the U.S. Department of Health and Human Services (HHS) Poverty Guidelines. Families are considered to be in poverty if their pre-tax money income (that is, not including in-kind benefits such as food stamps and not including the earned income tax credit) is less than a money income threshold that varies by family size and composition. The thresholds are updated annually to reflect inflation as measured by the Consumer Price Index.

For 2018, the federal poverty level was $25,100 for a family of four. Children living in families with incomes below the federal poverty level are referred to as poor. But research suggests that, on average, families need an income of about twice the federal poverty level to meet their basic needs. The way in which the poverty level is calculated is currently being reconsidered because it does not account for expenditures on things such as housing and child care (Annie E. Casey Foundation, 2015). The current threshold is also 'one-size-fits-all' for the 48 lower states and the District of Columbia and does not address non-cash assistance programs that mitigate some effects of poverty, such as food stamps and the Supplemental Nutrition Assistance Program.

The United Way has undertaken the ALICE (**A**sset **L**imited **I**ncome **C**onstrained **E**mployed) project to address the needs of families who live above the federal poverty threshold but who do not have the means to meet the basic costs of living, referred to as the ALICE threshold. The ALICE threshold varies by county and provides geographically specific estimates of what it really takes for working families to survive. In Sarasota County, for 2018[1], the last year reported in the ALICE report, it would take $62,040 or $31.02 an hour to be able to afford a survival budget that reflects housing, child care, food transportation, taxes, health care and miscellaneous expenses for a family of four. As noted above, the federal poverty level was $25,100 for a family of four in the same year. For the number of families in poverty with children by the number of family members, see Table 7.

Table 7: Poverty Thresholds for 2017 by Size of Family and Number of Related Children under 18 years

Size of family unit	Weighted average thresholds	Related children under 18 years								
		None	One	Two	Three	Four	Five	Six	Seven	Eight or more
One person (unrelated individual):	12,488									
Under age 65	12,752	12,752								
Aged 65 and older	11,756	11,756								
Two people	15,877									
Householder under age 65	16,493	16,414	16,895							
Householder aged 65 and older	14,828	14,816	16,831							
Three people	19,515	19,173	19,730	19,749						
Four people	25,094	25,283	25,696	24,858	24,944					
Five people	29,714	30,490	30,933	29,986	29,253	28,805				
Six people	33,618	35,069	35,208	34,482	33,787	32,753	32,140			
Seven people	38,173	40,351	40,603	39,734	39,129	38,001	36,685	35,242		
Eight people	42,684	45,129	45,528	44,708	43,990	42,971	41,678	40,332	39,990	
Nine people or more	50,681	54,287	54,550	53,825	53,216	52,216	50,840	49,595	49,287	47,389

Source: U.S. Census Bureau.

In Sarasota (2016), 7.9% of households received Supplemental Nutrition Assistance Program, more commonly known as food stamps (Food Research and Action Center, 2018). In Florida, less than three percent of Florida households below the federal poverty line received Temporary Aid to Needy Families, which in Florida is $303 per month for a family of three and is usually time-limited to 48 months.

1 The report is 2018, but the data are from 2016.

Children in poverty. Of the 41,926 people living in poverty in Sarasota County in 2017, 23.4% of them were under 18 years of age. The CCDs with the highest proportion of young children living in poverty are Interior County, Sarasota, and North Port.

Table 8: Children under Age 18 in Poverty, 2017

	Number	Percent
Florida		
Population for Whom Poverty Status is Determined	19,858,469	
Income in the Past 12 Months Below Poverty Level	3,070,972	
Children Under 18 in Poverty	901,772	29.4
Sarasota County		
Population for Whom Poverty Status is Determined	399,253	
Income in the Past 12 Months Below Poverty Level	41,926	
Children Under 18 in Poverty	9,824	23.4
Engelwood, CCD		
Population for Whom Poverty Status is Determined	11,740	
Income in the Past 12 Months Below Poverty Level	1,354	
Children Under 18 in Poverty	252	18.6
Gulfgate Estates-Osprey, CCD		
Population for Whom Poverty Status is Determined	28,452	
Income in the Past 12 Months Below Poverty Level	2,168	
Children Under 18 in Poverty	357	16.5
Interior County, CCD		
Population for Whom Poverty Status is Determined	34,644	
Income in the Past 12 Months Below Poverty Level	2,483	
Children Under 18 in Poverty	671	27.0
Longboat Key, CCD		
Population for Whom Poverty Status is Determined	4,653	
Income in the Past 12 Months Below Poverty Level	193	
Children Under 18 in Poverty	0	0.0
North Port, CCD		
Population for Whom Poverty Status is Determined	66,613	
Income in the Past 12 Months Below Poverty Level	8,190	
Children Under 18 in Poverty	2,110	25.8
Sarasota, CCD		
Population for Whom Poverty Status is Determined	184,514	
Income in the Past 12 Months Below Poverty Level	21,509	
Children Under 18 in Poverty	5,642	26.2
Venice, CCD		
Population for Whom Poverty Status is Determined	68,637	
Income in the Past 12 Months Below Poverty Level	6,029	
Children Under 18 in Poverty	792	13.1

Source: ACS B17001

Families and poverty. The Annie E. Casey Foundation's 2018 Data Book reports that 19% of US children and 21% of Florida's children live in poverty. When examined by race and ethnicity, a high percentage of children of color live in poverty with 32% of African-American / Black children, and 25% of Hispanic / Latino children living in poverty as compared to 12% of their non-Hispanic White peers. When these data are reviewed for families in Sarasota County, similar patterns are observed.

Affordable Housing

One of the building blocks for helping families out of poverty is stable, affordable housing. In Sarasota, 33.3% of children live in families who have housing costs that exceed 30% of household income (Florida KIDS COUNT, 2018), a commonly used metric for housing cost burden. In Sarasota County, among households making 30% of the average median income, there were 15,724 households that spent more than 50% of their income on housing (University of Florida, 2016), which is defined as severely cost burdened. In 2017, Sarasota had a deficit of 10,311 affordable and available housing units. Stated otherwise, for every 100 renters, there were only 19 affordable and available units.

Homeless children, youth and families. Between 2016 and 2018 there was an 18% decrease in the number of homeless in Sarasota and Manatee Counties (Suncoast Partnership, 2018). However, there were still 1,192 homeless individuals from 1,010 households. There were 238 individuals from adult and child households and 16 child only households. The number of homeless families increased eight percent in Sarasota County between 2016 and 2018. Among these households there were 160 children under the age of 18. There were 65 individuals 18-24 who were homeless across the two counties.

Mental Health Needs

Method. Permission to review Department of Children and Families (DCF SAMH) Substance Abuse and Mental Health general revenue funded services for the period July 1, 2014 – June 30, 2018 for children, youth and young adults who identified Sarasota as their county of residence was obtained. To be included in the analysis, individuals had diagnoses of autism, schizophrenia and psychoses, bipolar and related disorders, depressive disorders, personality disorders, trauma and stress-related disorders, obsessive compulsive disorders, disruptive behavior disorders, impulse control disorders, attention deficit hyperactivity disorder, and anxiety disorders. Service data were also reviewed for individuals considered at-risk. 4,862 unduplicated individuals received services in those four fiscal years. It should be noted that these data provide a partial view of mental health service use, as there are two other primary payers in Sarasota, Medicaid and county funds. The Medicaid data available did not include Outpatient services and so could not be used for this report.

Demographic characteristics. In those four fiscal years, the age groups of those served with DCF SAMH general revenue funds were young adults 18-25 years old (N=2,342, 48%), adolescents ages 12-17 (N = 1,383, 28.4%), elementary-aged children ages 6-11 (N = 989, 20.3%), and young children ages 0-5 (N = 148, 2.0%). The race and ethnicity of those receiving services were White non-Hispanic (N=3,337, 68.6%), Hispanic (N = 691, 14.2%), Black non-Hispanic (N=607, 12.5%) and other Non-Hispanic (N=227, 4.7%). To gain an overall profile of children, youth, and young adults served, DCF population groups were simulated[2]. 16.5% (N=800) of individuals in the analysis belonged to the Severe Emotional Disturbance population group, 31.2% (N=1,516) belonged to the Emotional Disturbance population group, 3.2% belonged to the At-Risk or other child diagnosis group (N=204), 42.2% (N=2,053) belonged

2 This algorithm is available upon request.

to the Serious and Persistent Mental Illness (SPMI) population group, and 5.9% (N=289) were adults whose diagnoses were not considered SPMI.

Service use and cost. For pre-schoolers ages zero to five, the three most common diagnoses were Emotional Disturbance of Childhood / Adolescence (31.6%, N=42), Attention Deficit Hyperactivity Disorder (19.6%, N=26), and trauma diagnoses (8.3%, N=11). There were 187 youngsters in this group[3]. These children used Crisis Services most commonly (N=105, 56.1%), Behavioral Health Outpatient Services (N=38, 20.3%), and Behavioral Health Assessment Services (N=22, 11.8%). A total of $91,739 was spent on this age group across the four fiscal years included in this analysis. See Table 9 below.

Elementary-aged children were most commonly diagnosed with Attention Deficit Hyperactivity (49.5%, N=355), Emotional Disturbance of Childhood / Adolescence (30.4%, N=218), and trauma diagnoses (18.4%, N=132). For elementary-aged children, a total of $664,135.39 was spent on 1,767 children across the four fiscal years. The services expenditures were most commonly for Behavioral Health Outpatient services ($281,439.13, 38.9%, N=689), Behavioral Health Assessment ($224,779.48, 26.5%, N=468), and Crisis Care ($116,240.04, 13.1%, N=232).

Adolescents were most commonly diagnosed with Depressive and Bipolar Disorders (42.3%, N=442), ADHD (25.4%, N=265), and trauma diagnoses (21.3%, N=223). Service use for adolescents ages 12-17 showed similar proportions of expenditures with the largest amount spent on Behavioral Health Outpatient services ($419,410.16, 39.5%, N=1,027), Behavioral Health Assessment ($299,664.35, 27.9%, N=725), and Crisis Care ($142,529.86, 9.5%, N=246).

Young adults were most commonly diagnosed with Depressive disorders (63.3%, N=1,159), Secondary Substance Abuse Diagnoses (44.5%, N=815), and Schizophrenia (20.9%, N=383). For young adults ages 18-25, the expenditures differed from younger age groups. Crisis Services was the largest expenditure ($1,209,000.18, 38.7%, N=1,527), followed by Behavioral Health Outpatient services ($425,099.88, 22.3%, N=879) and Residential Behavioral Health ($328,405.29, 1.1%, N=45). Other large expenditure categories were Other Behavioral Health services ($219,808.77, 2.3%, N=90), Behavioral Health Targeted Case Management services ($166,082.75, 3.6%, 144), and Assertive Community Treatment ($151,875.75, 1.7%, N=66).

Table 9: Costs by Age Group

Age Group	Total Claims	Total served	Total Cost
0-5	2,495	187	$91,739.02
6-11	11,636	1,767	$664,135.39
12-17	14,383	2,603	$936,570.94
18-25	26,676	3,948	$2,792,900.18

Length of stay. The amount of time spent in services was also examined across all fiscal years. For the group overall, most spent two to six months in services (31.9%), 22.2% had a single contact with an episode funded with DCF SAMH general revenue dollars, 19.9% had less than one month's time in services, and 11.5% spent seven to twelve months in services. When examined by age group, the majority in each of the 0-5, 6-11, and 12–17 age groups also spent two to six months in services. Young adults, however, had a different pattern with the largest proportion having a single contact with the DCF SAMH general revenue funded mental health system (31.7%, N=580).

3 Individuals served were unduplicated within, not across fiscal years.

Table 10: Length of stay by age group across four fiscal years

	All youth (N=3727*)		0-5 (N=133)		6-11 (N=717)		12-17 (N=1045)		18-25 (N=1832)	
	N	%	N	%	N	%	N	%	N	%
1. A Single Day	829	22.24	10	7.5	95	13.2	144	13.8	580	31.7
2. A Month or Less	742	19.91	30	22.6	92	12.8	164	15.7	456	24.9
3. 2-6 Months	1192	31.98	81	60.9	310	43.2	404	38.7	397	21.7
4. 7 Months to a Year	430	11.54	**	**	100	13.9	172	16.5	151	8.3
5. Up to 2 years	328	8.80	**	**	70	9.8	112	10.7	142	7.8
6. Up to 3 years	150	4.02	**	**	41	5.7	40	3.8	68	3.7
7. More than 3 years	56	1.50	**	**	**	**	**	**	38	2.1

* These calculations reflect length of stay unduplicated across fiscal years.
**Cells with Ns less than 10 are not reported due to confidentiality.

Service use of individuals with single contacts was examined by age group. For young adults, those with single contacts used Crisis Services predominantly (N = 594, 68.2%). For adolescents, those with a single contact used primarily Behavioral Health Assessment (N=68, 31.8%) and Outpatient Services (N=101, 47.2%). A similar pattern was observed for elementary-aged children with Behavioral Health Outpatient Services (N=70, 46.9%), Assessment (N=48, 28.2%), and Behavioral Health Treatment Planning (N=33, 22.1%) being most commonly used among those with single episodes of contact.

Calls to the 211 help line. Call data were reviewed for calendar year 2018. In this time frame, there were 52,362 requests for assistance. The top six categories for which assistance was requested was for housing and shelter (41.4%, N=21,657), utilities (32.0%, N=16,771), food assistance (10.2%, N=5,336), healthcare (3.2% N=1,682), employment and income (2.5%, N=1,324), and mental health and addictions (2.0%, N=1,032). Among the requests for mental health assistance, 45.0% (N=464) were for mental health services, 38.1% (N=393) were requests for substance abuse and addictions, 10.1% were related to crisis intervention and suicide (N=104), and the remaining 6.9% were related to mental health facilities. The top five Sarasota County zip codes that these requests came from in rank order were 34234 (N=108), 34223 (N=84), 34232 (N=58), 34236 (N=36), and 34237 (N=36).

Sarasota County's 2019 budget is $1.2 billion dollars, including $17,321,756 for Human Services (Sarasota County, 2019), including behavioral health. This amount includes $5,849,569 in the Core Human Services programs (Sarasota County, 2018a) and $4,237,492 to fund programs and services recommended by the Human Services Advisory Council (HSAC) (Sarasota County, 2018b).

The Core Services includes Comprehensive Treatment Court, crisis screening and stabilization services, 211, Teen Court, VIPER, the Addictions Receiving Facility and treatment for sex offender. Funding for these services is $3,698,080 and is intended to serve 27,238 individuals including 13,728 who receive information and referral services through 211. Mental health services included in the Core Human Service budget constitute 63.2% of the total Core budget. The HSAC budget includes $1,261,449 funding for behavioral health services that are expected to serve 8,847 people[4]. Funded services include outpatient counseling, peer services, early childhood services and supported employment. These services constitute 29.8% of the total HSAC budget.

4 Services provided to seniors were excluded.

Adverse Child Experiences (ACES). There is increasing recognition that experiencing trauma and adverse experiences in childhood, such as abuse and neglect, incarceration of a family member, or substance abuse or mental health issues by a household member has lifelong implications for mental and physical well-being. These traumas can also impact future substance use and can even increase the likelihood of premature death (Felitti, Anda, Nordenberg, Williamson, Spitz, Edwards et al, 1998). Building on this work, the Centers for Disease Control Institute developed an ACE module for use in the Brief for Behavior Risk Factor Surveillance System (BRFSS) as assessment of adult risk behaviors administered nationwide. The 2010 BRFSS included a module with five of these ACE indicators which was administered in Florida (Bright & Yu, 2010). This module was expanded to eight indicators in the 2014 administration (Holicky, & Phillips-Bell, 2016). These authors found that in Florida, the proportion of adults that experienced three or more adverse childhood experiences was 25.8%. For children, researchers at the Department of Health used the National Survey of Children's Health to calculate ACES based on nine indicators. In this study, 48.3% of children had not experienced any adverse childhood experiences, 28.5% experienced at least one, and 23.2% experienced two or more. The 2010 study, which addressed county level differences in the number of ACEs experienced, found that between 10 and 20% of adults in Sarasota experienced at least one ACE (Bright, Alford, Yu, Junwei & Jiang 2010).

Using these two studies' findings and applying them to Sarasota County's population, between 33,986 and 67,972 adult residents has experienced one ACE, and 17,009 children has experienced at least one ACE. The report also reminds us that children involved with the mental health, substance abuse, juvenile justice, and/or child welfare system have a higher prevalence of ACEs than the population overall. Florida's Department of Juvenile Justice (Baglivio, Epps, Swartz, Huq, Sheer & Hardt, 2014) has a body of research that documents that between 66% and 97% of Florida juvenile offenders reported experiencing at least one ACE, most commonly family violence, parental separation, or divorce and household member incarceration.

Capacity of Service Providers to Provide Trauma-Informed Services

Method. Using a survey conducted by the Circuit 12 Trauma-informed Care Committee, convened by DCF, results from providers who identified themselves as serving Sarasota County only (N=31) or who served the entire Circuit were included (N=20). A total of 51 people responded who met this criteria. These were primarily non-profit behavioral health providers (N=20, 39.2%), those who identified as 'other' (N=16, 31.4%), and government representatives (N=7, 13.7%).

Respondents were asked to rate their familiarity with what Adverse Child Experiences (ACES) are using a scale ranging from 0, or 'No Familiarity', to 7, or 'Greatest Familiarity'. Respondents were generally familiar with ACES, with 66% (N=31) rating their familiarity a 5 or higher. When asked about familiarity with scientific and clinical findings, 29.4% (N=15) reported that they were extremely aware, 41.2% (N=21) reported that they were somewhat familiar. 29.4% (N=15) were unfamiliar with the ACES study findings and the implications of childhood exposure to trauma and its effect on lifetime well-being. When asked what they considered the primary purpose of the ACES survey to be, the vast majority of respondents were focused on how knowledge of the ACES could help serve individuals better. Fewer (N=8) were focused on how knowledge of the ACES could be used to enhance provider capacity to provide trauma-informed services at the community level to understand the impact of the ACES on public well-being, and to identify gaps in the service array. Similarly, when asked how they would use the data, respondents were most focused on how it would improve care to their patients (75.6%, N=41) and less focused on how knowledge would help identify community resources for individuals exposed to traumatic events or for community level activities like assistance in a strategic planning process or primary prevention activities. Most respondents felt it was

important to include information about trauma in an individual's medical or primary care record (84%, N=42).

When asked whether they administered the ACE questions to clients served in their agency, about one quarter responded affirmatively (N=14, 27.5%), and for those who reported how long it had been used (N=7), four had used it less than two years. All of these respondents reported using it as part of assessment and patient education. For those who have not implemented ACE questions, they were asked to identify why they hadn't. The most common reasons that respondents reported that they didn't were because they didn't have enough knowledge about it or lacked training for their staff, (N=5, 22.7%), that they weren't required to collect data on ACES (N=3, 13.6%), or that they didn't know why they didn't collect that data (N=4, 18.1%). Some reported that they collected the information covered by the ACE survey or about trauma, but did not use a specific tool to do so (N=3, 13.6%).

Recommendations

The following recommendations have been developed based on the data outlined above:

- Prevention and community-based services: Based on review of these data related to mental health, the general revenue service system is crisis-oriented and deep-end focused rather than prevention oriented. Services like targeted case management that would help people better navigate the system are less commonly funded than services like outpatient and residential services on the opposite ends of the continuum. Sarasota County's behavioral health dollars contribute substantially to outpatient and community–based services as do Medicaid dollars, though the latter were not available for this report.
- Treatment for transition-aged youth: There needs to be a focus on treatment for co-occurring disorders particularly in the young adult population. With 20% of young adults displaying schizophrenia, ensure that new research drives treatment choices on first episode psychoses. Other supports similar to those funded through the Healthy Transitions model would benefit this population.
- Focus on family, youth, and young adult engagement in services: There is limited engagement of children, youth, and young adults with services for a substantial part of the population as evidenced by the proportion of single contacts with DCF services with no further contact and by interviews with caregivers, youth and young adults reported elsewhere.
- Focus on increasing awareness of trauma: Continue and expand the use of the ACE study to increase community awareness of the prevalence of ACEs. Affirm and support work at the individual child, family, or consumer level regarding ACEs but help expand the perspective to organizational and community/system level in both preventing trauma and a community response to working with individuals who have experienced trauma. Increase provider capacity for trauma-informed and trauma-specific interventions. This is an also an area around which primary care providers should be engaged in for children and families in their practices and children with special health care needs in medical homes (American Academy of Pediatrics, 2014).

Objective 2: Report Card

Sarasota County has experience with health report cards and has used a community engaged process for identifying measures of interest and importance to the community through SCOPE (Sarasota County Openly Plans for Excellence, 2014) and through the Sarasota County Department of Health's Community Health Improvement Plan process. SCOPE developed a report card based on the Jacksonville Community Council Inc. model. This report card included a section on demographics including the following domains: 1) Learning, 2) Economics, 3) Health, 4) Social, 5) Civic Participation, 6) Built Environment (Housing and Transportation), 7) Natural Environment, and 8) Culture and Recreation. The Health domain included infant births, infant deaths, rate of HIV / AIDS in the population, obesity rate, and suicide rate by age. While SCOPE, and hence its scorecard, was disbanded, the process used to identify these indicators relied on community review and consensus process, an important model that is also used in the Community Health Improvement Plan process.

Behavioral Health is already a strategic focus for Sarasota in its Community Health Improvement Plan. This plan includes the following indicators in the mental health category: 1) Average number of unhealthy mental days for the past 30 days for adults with an income less than $25,000, and 2) (Increase) the percentage of homeless adults with mental health problems who receive mental health services. The report card also includes indicators that impinge on mental well-being, though not explicitly considered 'mental health' measures, including access to health insurance, ability for adults with incomes under $25,000 to get a medical checkup, and the number of adults who were unable to see a doctor due to cost.

The Sarasota County Community Health Improvement Plan is currently undergoing review and revision in preparation for the next planning cycle. Consideration should be given to expanding the Community Health Improvement indicators to ensure that prevalence of mental health disorders, access to mental health care, perceptions of well-being, as well as outcomes are represented for both the child, young adults, and adults. In addition, to address the specific needs of young adults, adding the 18-25-year-olds as an age category is recommended.

In weighing the cost of additional measures, consideration has to be given to existing data sources relative to collecting new measures and the information systems necessary to house them and the resources to collect, clean, and report these data. Considering secondary data as a source, there are existing data that can be used to address each of these domains. One source is the Florida CHARTS data set. This reporting resource already collects data from sources including Florida Department of Health, Department of Education, Agency for Health Care Administration and others and reports on the mental health indicators contained in Appendix A.

Prevalence

With respect to prevalence, Florida CHARTS already reports mental health services to children ages 1-5. These data, provided by the Department of Children and Families, might be expanded to include older children, young adults, and adults. This might also be expanded by amending the data use agreement with the Agency for Health Care Administration to report the age services paid for by that organization, since they are a larger payer of publicly funded mental health services.

Access

For adults and young adults, there are already indicators that approximate access indicators, health insurance coverage. These data are available through Census Bureau or potentially Florida KidCare and could be added for children.

Perceptions of Well-Being

This is a domain that should be added for children. The current average measure of unhealthy mental days is an approximation of that measure. For children these data would have to come from another data source. The Youth Risk Behavior Survey includes measures related to functional impairment due to depression as well as suicidal ideation and attempts that could be used as proxy measures for mental well-being.

Recommendations

The Community Health Improvement indicators should be expanded to address adults, young adults, and children and the following domains should be included:

- Prevalence of mental health disorders
- Access to mental health care
- Perceptions of well-being as well as outcomes represented for both the child, young adults and adults

Objective 3: Primary Care Provider Survey

Introduction

One objective of the Environmental Scan was to examine the current capacity of primary care providers in Sarasota County to assist with the growing demands of mental health needs for children, adolescents, and young adults in their care. The purpose of this objective was to gather insights from primary care providers and pediatricians regarding their role in linking individuals (0-24) to mental health services.

Methods

Members of the evaluation team compiled a list of primary care providers and pediatricians in Sarasota County. The list was derived from an in-depth Google search and a search of the provider's websites. The list had 105 providers on it. The list of providers was shared with evaluation partners at the Barancik Foundation and members of the Department of Health. An evaluation team member called each provider's office to recruit physician participation. The response rate of physicians was low, so the evaluation team member visited physician offices in-person in Sarasota County. Despite these efforts, the total survey response was obtained from only two providers.

Findings

Findings from these physicians were incorporated below in Objective 4. An evaluation team member made multiple phone attempts to recruit physicians, and conducted some in-person requests for participation. The evaluation team also extended the deadline for survey completion and collaborated with the Project Liaison to identify and reach out to key stakeholders who could help disseminate the survey and garner more response. Despite these efforts, there were only two physician participants who completed the survey, and therefore the results of the survey cannot be generalized. However, the physician participants did offer insight into how they refer patients to mental health services and the impact of untreated mental health on the general population, and their comments are congruent with the comments presented in the stakeholder and parent interviews. This low response-rate may also be reflective of the lack of connection between mental health and primary care systems and the difficulty engaging primary care providers in mental health. With an ever -increasing focus on the integration of primary and behavioral health, this should be an area of outreach and engagement as implementation begins for the next phase.

Objective 4: Barriers and Challenges to Improving Mental Health

In order to understand barriers and challenge to improving the system of mental health care for youth in Sarasota County, the evaluation team elicited feedback from the community through several activities in order to gain direct insights. Findings from the stakeholder survey and interviews, and parent and youth interviews and focus groups follow.

Stakeholder Survey

The evaluation team garnered feedback from stakeholders through two methods. First, a stakeholder survey was administered throughout the county to explore how communities are implementing values and principles consistent with effective systems of care. The survey was heavily adapted from the System of Care Implementation Survey (SOCIS) used to assess implementation of an array of strategies that may be used to expand the System of Care approach. The survey was administered to partners engaged in various agencies and organizations throughout the county who serve and/or support children, youth, and young adults impacted by mental illness. The SOCIS is a 70-question survey based on the conceptual framework for System of Care implementation (Kutash, Greenbaum, Wang, Boothroyd, & Friedman, 2011). The large majority of the domains assessed in the SOCIS were included in the Sarasota County Mental Health Assessment Stakeholders Survey:

- Family/Youth Choice and Voice
- Individualized, Comprehensive, and Culturally Competent Treatment
- Outreach and Access to Care
- Transformational Leadership
- Interagency and Cross-Sector Collaboration
- Values and Principles
- Skilled Provider Network
- Performance Measurement System
- Provider Accountability
- Management and Governance
- General System Performance

An additional domain was added to assess respondents' perceptions regarding the impact of untreated mental illness in Sarasota County.

Methods

Survey administration for the Sarasota County Mental Health Assessment Stakeholders Survey began in August 2018. The USF project team collaborated with the project liaison, Leah Duncan, to distribute the survey to key stakeholders, and it was also shared with members of the Sarasota Behavioral Health Stakeholders Consortium with encouragement to distribute widely. As a follow-up, to increase response rate, two reminder emails were sent to those prospective survey respondents who had not yet participated in the survey.

Data Analysis

Most items in the Sarasota County Mental Health Assessment Stakeholders Survey are rated on a Likert scale from 1 to 5, with higher ratings indicating greater implementation of values and principles consistent with effective systems of care. Some items indicated a "yes/no" response. For data analysis, these items were fit into the 1 to 5 ranking such that a "yes response was recoded as a "5" and a "no" response was recoded as a 1. This way, a composite score for each domain could be computed. A similar strategy was used to fit two 7-point items on a 5-point

scale. To reduce the amount of missing data, a response to each item was forced in the online survey management software. However, participants were able to indicate "I don't know" as a response so that composite scores were not misleadingly skewed by random responses (Greenbaum, Wang, Boothroyd, Kutash, & Friedman, 2011).

Results

Fifty-one respondents completed the Sarasota County Mental Health Assessment Stakeholders Survey. Most respondents indicated they worked in a mental health provider agency (33.3%, n=17) and seven participants were employed by the school district (13.7%). Other agencies and organizations represented included, for example, advocacy groups, the Sheriff's Office, child welfare, the Early Childhood Coalition, the Department of Health, substance abuse treatment providers, non-profit organizations, and physical healthcare providers. Most respondents held administrative roles (33.3%, n=17) in their workplace and several others were therapists and counselors (15.8%, n=8) or social workers and case workers (11.8%, n=6). Clinicians (3.9%, n=2), nurses (8.0%, n=4), teachers/instructors (5.9%, n=3), and persons who held executive positions within agencies (8.0%, n=4) also participated in the survey.

Table 11 provides descriptive data for each domain assessed by the Sarasota County Mental Health Assessment Stakeholders Survey. Domains are presented in rank-order to organize varying levels of System of Care implementation. Recall that higher scores indicate greater implementation. Average domain scores ranged between 1.82 (Skilled Provider Network) to 4.26 (Interagency and Cross-Sector Collaboration) with an average overall level of implementation of 3.20 (on a scale of 1 to 5). Two domains have an average rating above a "4" indicating greater implementation of values and principles consistent with effective systems of care. These include Interagency and Cross-Sector Collaboration (4.26) and Values and Principles (4.16). Noteworthy scores were also observed for Individualized, Comprehensive, and Culturally Competent Treatment (3.66), Provider Accountability (3.29), and Outreach and Access to Care (3.09). Respondents rated General System Performance (2.41) and Skilled Provider Network (1.82) as having the lowest level of implementation of values and principles consistent with effective systems of care.

Table 11: Rank-Ordered, Average Stakeholder Survey Scores

Domain		Mean (SD)
Interagency and Cross-Sector Collaboration	(n=48)	4.26 (2.26)
Values and Principles	(n=24)	4.16 (1.54)
Individualized, Comprehensive, and Culturally Competent Treatment	(n=48)	3.66 (.82)
Provider Accountability	(n=32)	3.29 (1.74)
Outreach and Access to Care	(n=51)	3.09 (.38)
Transformational Leadership	(n=42)	2.96 (.98)
Management and Governance	(n=31)	2.95 (.80)
Family/Youth Choice and Voice	(n=51)	2.82 (.64)
Performance Measurement System	(n=35)	2.43 (1.41)
General System Performance	(n=40)	2.41 (1.19)
Skilled Provider Network	(n=43)	1.82 (.95)
Total Level of Implementation	**(n=51)**	**3.20 (.57)**

Findings for the Unmet Need section of the survey are discussed under Objective 5 of this report.

Discussion

The findings reported here detail results from the Sarasota County Mental Health Assessment Stakeholders Survey. These surveys were adapted from a tool designed to measure implementation of values, principles, and strategies consistent with systems of care. Results suggested several values and principles were being well-implemented throughout Sarasota County including collaboration across agencies and child-serving systems, providing care that was individualized, comprehensive, and culturally competent, provider accountability, and access to care. Survey results also identified areas in which the county might target efforts to improve services and supports for those affected by mental illness, especially in the areas of performance measurement, general system performance, and in having a skilled provider network. (For a summary of open feedback from respondents, see Appendix B).

Of particular importance, findings from the Sarasota County Mental Health Assessment Stakeholders Survey also highlighted several consequences of untreated mental illness including behavioral disruptions in school, health risk behaviors, and overcrowding in jails in prisons. According to participant's experiences, untreated mental illness also impacted the child abuse and neglect, the workforce, and homelessness.

Stakeholder Interviews

In order to gain a more robust understanding of the perspectives of stakeholders, the project team conducted interviews with a smaller sample of stakeholders. The interview protocol was adapted from the 2017 St. Louis Youth Behavioral Health Community Needs Assessment (Behavioral Health Network of Greater St. Louis, 2017) and includes the following domains:

- Introduction and Role
- Resources and Assets
- Barriers and Weaknesses
- Collaboration and Coordination of Services
- Strengths and Opportunities
- Additional Recommendations and Feedback

Methods

Key stakeholders were identified through multiple methods: 1) stakeholders who completed the survey had the option of volunteering to take part in interviews, 2) stakeholders who were involved in the mental health scan process suggested individuals or agencies to contact for interviews, and 3) the project team and Project Liaison strategically identified interviewees to ensure perspectives from all major stakeholders were included.

A total of 26 stakeholders participated in interviews. Members of the project team conducted interviews by phone, with each one lasting approximately 30 minutes to one hour. Interviewers reviewed the study with each participant and asked for verbal consent to take part in the study. Interviews were recorded with participants' permission; in cases in which participants declined to be recorded, the interviewer took notes.

All stakeholder interviews were transcribed into electronic documents in order to conduct thematic analysis based on the domains above. Several members of the study team coded the transcripts using *Atlas.ti* qualitative analysis software. Prior to coding, team members conducted an inter-rater reliability exercise and reached an agreement rate of 81%, indicating consistent interpretation of the coding scheme.

Findings

Key findings from each of the domains are presented below.

Role. The interviewees represented community mental health providers, substance abuse providers, child welfare organizations, the Department of Juvenile Justice, the Sarasota County School System, the Department of Health, Sarasota County Department of Health and Human Services, community organizations, law enforcement, newspaper outlets, Sarasota County National Alliance on Mental Health (NAMI), Sarasota County Board of County Commissioners, non-profit foundations, and early childhood care providers. Interviewees had experience in their roles that ranged from less than one year to approximately 34 years.

Characteristics of the population. When asked about the characteristics of individuals seeking services, most interviewees reported that individuals experiencing poverty, mental health disorders, substance use disorders, and abuse and trauma predominantly sought services in Sarasota County. One interviewee expressed: "52% of County youth live in poverty." Another interviewee reflected on the types of mental health disorders being seen in Sarasota County youth, "I can tell you we have children who have anxiety disorders, obsessive compulsive behaviors. We have children who have been diagnosed with bipolar issues, schizophrenia, attention deficit hyperactivity disorders." Another interviewee expressed how these mental health disorders become a serious concern for parents when the youth becomes a young adult over the age of 18,

> Parents are trying to get kids to get into treatment, attend appointments, and take medications, [etc.]. They're often paying, supporting financially both for their medical care as well as the accommodations, and there are a lot of conflicts. Two women in the group, both of them had daughters in their early 20s, who were refusing to speak to them. They were aware that they were quite psychotic or they were manic. They were terrified for their safety.

Interviewees noted that Sarasota County was predominantly Caucasian. Interviewees also reported serving individuals affected by homelessness, youth with multiple diagnosis, uninsured youth and families, unaccompanied and at risk youth, students with dysregulation issues, juveniles with law violations, and youth and families with multi-generational issues.

Referrals. Not all stakeholders accepted referrals. For example, interviewees from law enforcement reported that they primarily make referrals to agencies and organizations. The stakeholder interviewees that worked for an agency or organization that would be responsible for accepting referrals mentioned school faculty and administrators as a primary source for referrals. Respondents from the Primary Care Provider Survey both reported that they have made over 100 referrals for mental health services over the past twelve months. Other referral sources reported were: advertisements, recommendations from other clients, having a presence within the community, sheriff's office, teen courts, parents, foster care, partners and collaborators, doctors, and google searches. One interviewee stated: "Referrals come from all over. They come from law enforcement, the school system, the families themselves, and friends. Some referrals come from our different funders that we have; some referrals come from the criminal justice system, the jail."

Available resources and programs. Multiple organizations and agencies were reported as places that individuals in Sarasota County could go to for mental health services. The primary mental health providers reported were Centerstone, Bayside Center for Behavioral Health, Coastal Behavioral Healthcare, the Florida Center for Early Childhood, First Step of Sarasota Inc., and Jewish Family and Children Services. (See Appendix C for a complete list of those named by respondents.) Interviewees noted that receiving services can be difficult for individuals based on their geographic location within the county: "If you happen to reside in the Southern half

of Sarasota County, some [services] are more limited without crossing over into Charlotte and going to Charlotte Behavioral Health or some of the other larger groups there." Interviewees also reflected on the difficulty accessing services:

> Services here are really hard to access, they're hard to navigate, and there aren't very many for kids. You know, the public providers certainly have kid programs, but still, they're not comprehensive. And even things like for kids that need more intensive services like IOPs or something, there just aren't any.

Met needs. Interviewees commonly stated that they felt Sarasota offered a wide-array of services including non-profit organizations, such as, NAMI, the Salvation Army, the Sarasota YMCA, and Bayside Center for Behavioral Health. However, despite the wide array of services, interviewees expressed that there were not enough services to meet the needs of teens and young adults. One interviewee said:

> I can definitely say, I'm always highly impressed with the Florida Center and what services they provide for those kids that are eight and under. I do think there's a gap on appropriate service provision for the old, you know the adolescents and the teen population.

Another interviewee said: "I think that a lot of needs are being met, but there just isn't enough, or there isn't enough visibility."

Barriers and weaknesses. Discussion of barriers and weakness include difficulty and ease of accessing services, visions for improving service access, unmet needs in mental health services for youth, and the impact those unmet needs have on individuals, families, and the broader community.

Barriers to service access. One area that was reported as a significant barrier to access among the majority of stakeholders was insurance coverage for services. Stakeholders discussed multiple ways that insurance coverage, or lack thereof, interfered with obtaining appropriate or sufficient services for both Medicaid and private insurance clients. For those who were on Medicaid, respondents discussed many limitations that prohibited youth from getting needed services, including lack of coverage of certain therapies, a limit on the number of hours or sessions of some services, and differences in Medicaid "zones," which can cause families to have to change services or providers when they move across zones, often resulting in significant lag times in service provision. There was strong consensus that Medicaid, in general, was extremely difficult to navigate for both families and providers, and it often prevented timely service provision. Several respondents discussed ways that Medicaid deterred providers from being able to serve more clients, such as having very low reimbursement rates or not being able to bill Medicaid for travel, preventing providers from doing more in-home services.

Even given these challenges, some responses indicated that clients who qualified for Medicaid had more service options available to them than those with private insurance. It was widely noted that many families with private insurance can't afford the cost of benefits that cover behavioral health, or they can't afford the deductibles. Respondents also discussed difficulties finding providers that accept specific plans and even when families did find a match, the wait time to begin services might be one to two months, which is potentially dangerous to individuals who need immediate help with mental illness. Finally, it was widely agreed that even when services could be initiated, there was not sufficient coverage for the number of sessions or amount of time many youth needed to be treated.

Another area that was described by interviewees as highly problematic is the lack of parents' awareness of service options. This includes not knowing what services are appropriate or available and how to go about finding the right services for children. Furthermore, many

respondents suggested that parents could not distinguish between common behavioral issues and those that might be indicative of mental health conditions. Some respondents pointed to ways that parents saw their children as simply "acting out" or thought, "I acted like this when I was a kid…they'll grow out of it." One interviewee noted that there was a general lack of education around stages of child development, which prevents parents from understanding what typical and atypical behaviors are and therefore neglecting to seek out help when it is otherwise warranted. This lack of understanding of mental health was also attributed to youth, who were described by several respondents as not being aware that they needed help or could get help for the challenges they were experiencing. As one interviewee noted,

> …One of the biggest barriers is the kiddos and the realization. You know, I've had kids come in and they just don't think they need to be here…they don't connect, "hey, I need to talk to an outsider about this and find some new ways to deal with it." And [they have] fear to say to anybody that there's something wrong.

Some interviewees also discussed the difficulties of finding providers that connected well with youth, with one suggesting that many mental health services for youth are "not conducive" to engaging children, youth, and young adults.

Many respondents discussed the lack of specialized services for various needs among children and youth in the community. Some of these issues reported by stakeholders include finding the right combination of mental health and medical services for lower functioning children, finding safe spaces like therapeutic residential facilities or single rooms for youth with sexualized issues, or obtaining follow up care for youth who enter crisis services and are released after three days. One respondent saw a discrepancy in which children have access to services, suggesting that, at the middle school level, students in juvenile justice, child welfare, and those with substance abuse have greater access to services, but there is very little available for "the other 99%" of students.

Another theme that strongly emerged among stakeholders is the logistical difficulties of accessing services, such as transportation and time constraints on families. Several respondents pointed out the lack of service options in the southern region of Sarasota County, including Venice and North Port, which therefore made for long travel times for parents who could only access services in the northern region of the county. One interviewee noted that it can take several hours to get to an appointment, only to spend one hour in the service and turn around and spend several hours going back home, essentially taking up the entire day. Respondents generally commented on the lack of public transportation options, like buses, and saw this as a barrier to services for many families. Compounding the issue, it was reported that many families simply don't have the time required to participate in services, especially within the timeframes that services are often offered. Most interviewees agreed that are many parents who cannot take time away from work on a regular basis and that there were not enough services available outside of the typical 8:00am to 5:00pm work day. It was also suggested that after-school hours were difficult to access because of that timeframe booking up quickly, leading some parents to take their children out of school for services. For parents who work multiple jobs, have changing shift times, or are in poverty, accessing services is reportedly especially difficult:

> I know that parents from poverty struggle with transportation and getting children to their appointments, and also job interference. Because, parents who are from poverty and are working are usually working low wage positions where they cannot take time off to meet the needs of their child if they want to keep their job…I think typically parents are not expecting to have to provide their child with mental health services.

This comment highlights the constraints that exist for many families, as well as the general incongruence between the mental health system of care and the community's structural capacity to facilitate that care.

Finally, it was widely reported among stakeholders that stigma prevented many families from accessing mental health services for their children. Some ways interviewees saw stigma affecting service outreach were youth not wanting to be different or having a fear of being bullied, parents not wanting to admit that there was a "problem" with their child, fear of being shunned by the community, and both parents and youth having a general sense of shame around potentially having a mental illness. One stakeholder describes the impact of stigma can have on families:

> Caregivers and family members are often looked at as if they did something wrong or differently with their child that they now have these behavioral issues or these mental health issues, whereas we know that's absolutely not the case and mental health isn't really tied very often to the parenting, it's not a result of bad parenting. So, I think that stigma coupled with a lack of knowledge of the resources out there creates the barriers to helping more children and families in need earlier on…

It was also suggested by some stakeholders that parents may be afraid of being "found out" for their own potential mental health issues, and that youth often don't know how or don't want to reach out for help on behalf of themselves.

Although the above themes were the most frequently commented during the interviews, stakeholders also discussed numerous other barriers to access, including high turnover rates and inconsistency in care, more urgent issues like housing instability taking precedence over mental health care, long wait lists to be seen, and general lack of a specific advocate or agency to guide families through the process of seeking out services.

Unmet need. There were a variety of responses related to child and youth mental health needs that are currently unmet. One theme that stands out more visibly than others is the need for prevention services. Many respondents discussed the lack of adequate prevention services during the early years, including early assessment and intervention during pre-school and lower elementary years, consistent screening for Adverse Childhood Events (ACES), and regular social and emotional programming incorporated into schools that address issues like bullying. Several respondents felt that mental health evaluation and social and emotional education should have resources equal to those of academic education, as they are just as important in children's lives. This reported need for prevention goes hand-in-hand with statements that indicate the current mental health system of care in Sarasota County is heavily focused on crisis services and deeper end services. Aside from a dearth of measures to prevent mental health crises from occurring, interviewees also shared that there are major gaps in follow-up services after youth have been treated for a mental health crisis. It was widely noted that there is a heavy reliance on Baker Acts because it is often the fastest way to get services, though this misuse of the system causes long-term problems because Baker Acts do not lead to long-term care management.

Several respondents highlighted the need for appropriate services for older teenagers and young adults. Many stakeholders agreed that there are specific needs for this age group that are inconsistent with the structure of mental health services. For instance, there are challenges around providing consistent services for teenagers who are "aging out" of youth services and beginning to qualify for adult services. This transition period was reported as challenging because providers may not want to begin treatment with a 17-year-old, for example, who will soon be 18 years old and have changes in coverage for services, which may mean a change in providers or treatment options. Furthermore, many youth in this age group are in transition in other ways, such as starting college or having an inconsistent residence. Finally, some respondents suggested that, even though young adults qualify for adult services, the treatment is not appropriate for them because they are still on a "bridge" between adolescence and adulthood.

Another area of need that was widely discussed was that of specific youth-focused services, ranging from community support resources to appropriate youth inpatient treatment. Some

respondents saw the need for community support groups for young children outside of school, particularly for younger children and for foster care youth because of the multiple traumas they experience through removal and placement. Some respondents stated that there is a need for a collaborative of professionals focused specifically on youth mental health. There was wide agreement that inpatient facilities for youth in the County are lacking. For foster care youth, it was repeatedly noted that there is a dire need for therapeutic foster care and group homes, and there was concern more broadly that residential treatment facilities for youth were lacking. Other respondents felt that there were few options for youth psychiatric treatment, particularly with regard to prescribing psychotropic medications. Comments also reflected a need for group therapy for children of any age that focused on coping strategies and life skills. Likewise, it was noted that there are not enough easily accessible healthy living resources that might be beneficial for older teens and young adults, such as yoga and mindfulness practice.

Stakeholders pointed to other ways that the community is not well-equipped to provide effective mental health services for children, youth, and young adults. Several respondents pointed out that the County is seeing more children with behavioral issues that may overlap with mental health concerns. One interviewee reported that there have recently been several Workman's Compensation claims from teachers being injured by children under five years old. Another stakeholder indicated that developmental needs services have been declining over recent years, and another noted that there is a lack of non-school behavioral supports in the community, particularly with regard to identifying the needs of children with Autism Spectrum Disorder. Other stakeholders felt that current services did not meet the needs of the diversity of constituents in the County in other ways, such as having enough Spanish-speaking providers or having providers truly knowledgeable about issues related to gender or sexual identity.

Impact of unmet need. Respondents had numerous observations of the ways in which all members of Sarasota County were impacted by the unmet needs described above. The major themes that emerged from this component of the interviews include impacts to individual and their families, school and academic outcomes, engagement with juvenile justice, economic costs to the community, and long-term and generational impacts.

Many stakeholders argued that the most worrisome impact of unmet needs is on the quality of life of the child or young adult who experiences mental illness. This may include low educational achievement, lack of future job skills, loss of opportunity for positive development, negative impact on current and future relationships, and in worse case scenarios, suicide. Respondents saw many ways that families were impacted by the stress and frustration of unsuccessful attempts to help children find treatment. Many respondents noted that families may socially withdraw and some may eventually give up after multiple failed efforts to get effective help. One respondent noted that it can be especially devastating for families when a child has their first psychotic break because it may signify that a long-term or life-long struggle is ahead. The following comment highlights the magnitude of the effects of unmet need on the family and individual:

> Well, it can be devastating as we know. I mean, if mental health isn't being met then the issues accelerate and become more pronounced, more severe, more frequent, parents don't know what to do, the kids don't know what to do, and the school systems don't know what to do. And everybody starts pointing at each other, which is, you know, really sad for the child because everybody just says, well, there's something wrong with this child, but nobody is, you know, giving them what they need.

Some interviewees indicated that this lack of knowledge of what to do can lead some parents to feel that they are unable to handle the challenges that come with their children's mental health needs and in some cases they may end up having their children removed.

Interviewees readily discussed the impact on schools, including students, teachers, and the general functioning of the school system. Many respondents described a "snowball effect" that begins in schools, in that when students' mental health needs are not met, they become disruptive and may do poorly academically, drop out of school, and/or become involved in criminal activity. The effects of untreated mental illness on other students and teachers were also frequently discussed. The disruptions caused by students with unmet needs often interfere with other students' learning. Furthermore, it was widely agreed that teachers are not equipped or trained to handle the behaviors that result from unmet mental health needs, and therefore the entire classroom and school becomes stressed and unable to operate as it is intended, which is detrimental to a field where there is already a critical shortage of teachers. Many stakeholders expressed frustration with the lack of effective mental health resources that existed in schools, and said that despite the idea that schools are meant to focus solely on academic education, the reality is that many children's mental health challenges present themselves during the school day, and therefore it becomes an issue for school. Many respondents pointed out the recent addition of mental health providers in schools, and this will be discussed further in the Strengths section below.

Stakeholders also widely agreed that there were obvious economic costs to the community when the mental health needs of children, youth, and young adults went unmet. It was clearly stated among stakeholders that it is more expensive *not* to address mental health needs fully when they are first presented. Furthermore, it leads to inappropriate use of services when early needs are not met. For instance, those with untreated and severe mental illness are at high risk for ending up in Emergency Rooms (ERs), crisis stabilization units, or jails, none of which are intended to provide comprehensive mental health treatment. One interviewee describes a pattern of escalating costs when multiple systems are utilized because of the lack of effective treatment from the start:

> …if we really just treated the person [sufficiently], it might be expensive but [if we] give them the duration they need, it's probably less expensive from a funding standpoint alone than just re-engaging in the crisis system. Whether that's, you know, the ER visits, whether that's the admissions to the crisis stabilization unit, the admissions to the addiction receiving facility, the admissions to jail, you know, the criminal justice system, all of those things. That's what happens when somebody is not provided or gets the level of treatment that they need.

This point emphasizes the crisis-based nature of the current mental health system, the costs of which are succinctly put into perspective by another respondent: "…we don't spend money for long-term duration care, but we're okay with spending the most expensive dollars by responding to a crisis." One respondent pointed out that the system becomes stressed the older youth become, and that more youth are entered into services than what would be necessary if preventive and early intervention services were adequate. Many comments also indicated a general loss of economic production due to the inability of many sufferers of mental illness to hold steady jobs, not to mention pay for housing, cars, or other basic necessities that would contribute to the economic health of the community.

In general, respondents discussed the magnification of issues that stress families and systems when mental health needs among youth are unmet. Many spoke to the mutigenerational cycle that occurs with unmet mental health needs. For instance, one stakeholder commented that many times, adults who have had untreated mental health challenges as youth or young adults are now at risk for involvement in child welfare and criminal justice systems, job instability, and homelessness. Some stakeholders commented that many of the individuals who come into jails have had past traumas that have led to mental health problems. Another respondent noted that, for parents who cope with their own mental illness in unhealthy ways (such as substance abuse), the effects on their children will be evident ten years from now: "They just don't get better.

The issues get magnified. The family dysfunction gets worse. The criminal behavior increases. The school issues increase. The substance abuse issues increase with mental health not being addressed." Even for parents without mental illness, respondents remarked, the stress of dealing with their children's mental health issues may lead some to turn to substance use as a way to cope, thereby engaging the family in the self-perpetuating cycle of dysfunction.

Visions for improving service access. Stakeholders shared many ideas for improving access to services and were generally in agreement about what components would be necessary for youth and their families to have necessary access to services. There was strong consensus that a multi-pronged approach that includes awareness, stigma reduction, infrastructure improvement, and more sustainable funding is the only way to make access to services easier for families: "it's a forked approach…you have to reduce the stigma and make people open to acknowledging and getting some assistance, and then you have to make that assistance available."

Respondents frequently suggested that families would have much better access to mental health services if there was a single point of contact or a system navigator to help them "connect the dots." Some interviewees noted that this was one of the findings from the First 1,000 Days initiative funded by the Barancik Foundation, and others saw this as a logical solution to the difficulties families and providers face in navigating services. Several stakeholders commented that getting help for mental health issues should be just as easy as getting help for a broken arm or leg; in that situation, people know exactly where to go and generally what the process will look like. Respondents also envisioned a system in which providers work with families all the way through their services until they have a successful resolution.

Stakeholders also agreed widely that good access to mental health services should include more in-home services and more hours of availability during evenings and weekends. Several interviewees discussed the possibility of accessing services via smartphone, tablet, or telephone, and some noted that one provider of these services, TeleHealth, would soon be available in the area.

Many respondents shared a vision of increasing access to school-based services as well. This included discussion of students and families having more access to qualified mental health works at school, and ensuring that they are paid appropriately and funded long-term so that they remain in their positions. It was also suggested that schools could serve as a starting point for early intervention if there was enough awareness of the option to talk to someone about mental health challenges. One stakeholder explains: "I think if we could have more school-based programming, it would help. You know, to a certain extent kids are a captive audience when they're at school, and then parents wouldn't have to worry as much about transportation."

Other respondents agreed with this point, but suggested pre-schools should be the starting grounds for assessing mental health issues. For any of the above efforts, stakeholders were in agreement that there needs to be some kind of anti-stigma campaign around mental illness.

Collaboration and coordination. This section includes discussion of ways in which providers and relevant agencies are expected to coordinate services and collaborate with one another. It also incorporates feedback about facilitators and barriers to policy and funding coordination.

Many stakeholders discussed ways that services are currently coordinated and named multiple agencies with which they made referrals, partnered with on various initiatives, and generally worked closely with in order to facilitate services for children, youth, and young adults. Much of this service coordination was described as "inter-agency," and involved mental and behavioral health care providers, law enforcement, child welfare, the Sarasota County Health Department, homelessness agencies, teen court, and Sarasota County Schools. Despite these existing efforts, many stakeholders expressed concern about the difficulties of coordinating services. Some of the reasons respondents said service coordination might not happen is because of lack of follow through or communication, policies or procedures that inhibit easy coordination, lack of time

and funding to take the steps necessary to coordinate care effectively, and competition over resources that may inhibit providers from helping each other.

Additionally, respondents pointed to numerous ways that policies presented challenges to service coordination. Insurance policies were frequently regarded as burdensome to service coordination, in that it is often difficult to determine which providers families can access and which services will be covered. Furthermore, it was noted that assessments for determining whether particular conditions will be covered can take months, and in the meantime, children may have a high risk of self-injury, harm to others, destruction of property, and more. Several interviewees also noted that concern over privacy and confidentiality laws prevented both providers and clients from sharing important information during service coordination.

Funding was another area that warranted strong feedback in terms of interference with service coordination. The general insecurity of funding for mental health services stood out to many respondents as a reason for not having strong service coordination. For example, though some funding has created effective programs, like parent advocates and support groups for youth mental health, when the funding is gone those programs disappear, leaving fewer resources to refer families to and more difficulties attaining sustainability. Also, when the resources for mental health are scarce, providers necessarily compete for funding, which may make some providers less inclined to reach out to specialists or other providers who may be able to help a client better because it affects their agency's bottom line.

With regard to collaboration, respondents were overwhelmingly positive about the efforts made among mental health stakeholders to rally around a common cause. Many referenced the Sarasota Behavioral Stakeholders Consortium as an engaged collaborative body well represented by behavioral health providers, law enforcement, child welfare, and others, though it was noted that the school district was often missing "at the table." Several other collaborative entities that were named included the Youth at Risk project, the Family Safety Alliance, the Community Alliance, and the Positive Youth Development Council, to name a few. While stakeholders agreed that these groups had strong potential for enacting change, it was suggested by many that the groups were more oriented around sharing ideas and learning from one another rather than implementing structural change.

Strengths. Stakeholders were asked to identify current strengths in Sarasota County's children, youth, and young adult mental health care and to discuss opportunities for improvement they saw as most beneficial to the community. For the most part, participants saw many existing strengths of the mental health community in Sarasota County. As mentioned above, the capacity for collaboration was seen as very strong and indicates that there is a widely shared "willingness and desire to do what's right" and to work together for the sake of children and families. Providers and other partners were described as genuinely wanting to help people and contribute to a healthy community. Stakeholders also described many smaller strengths that ranged from grassroots efforts to particular agencies or individuals, with many adding that local foundations were very invested in mental health outcomes. However, it was noted that these small successes are not enough to sustain the entire mental health system of care, and involvement in successful programs or services often depends on luck or personal connections.

Many respondents pointed to the increase in mental health providers in schools as a major strength. As a result of Senate Bill 7026, Sarasota County Schools was able to bring in twenty-one clinicians to provide mental health support to elementary and middle school students. Stakeholders saw this as hugely beneficial to teachers and students, and many were encouraged that this was the start of a culture shift in which acknowledging and discussing mental health issues at a young age would become more commonplace.

Opportunities for change. Responses to this component of the interview were well aligned, with some of the larger themes including more opportunities for community education, awareness, and training; having less "red tape" to work through; having a more structured approach to a whole system rather than individual silos; more availability of psychiatric services; and more strategic funding.

Better community awareness and education was recommended for both families and community agencies. For families, stakeholders felt that parents, especially, needed to be made more aware of available resources so they know more about mental health in general as well as how to go about securing services for their children and what to expect from them. It was also suggested that parents have better access to parenting education, both in terms of understanding child develop and also having tools to work with "difficult" children. Several stakeholders also called for consistent parent support groups where parents and caregivers of children with mental illness can share experiences, problem solve, and discuss successes. With regard to mental health education for community agencies, stakeholders proposed several types of cross-agency trainings, such as Mental Health First Aid USA, provider-hosted assemblies at schools, better funding mental health training for tangential agencies like law enforcement.

In terms of reducing "red tape" with mental health service provision, stakeholders commented that the many forms and processes families are required to complete are burdensome and unnecessary, especially when families are already struggling or in the midst of a mental health crisis with their child. Respondents called for a streamlining of paperwork so that processes are not duplicated and the very means to obtaining services are not a detriment to families. Many interviewees said they felt like they had to "jump through hoops" to find the right funding for services or get essential information like medical records. Some spoke to the misuse of HIPPA, which was intended to protect people from discrimination based on medical conditions, but is reportedly used by providers to avoid sharing information for fear of punitive measures.

Many stakeholders recognized the lack of congruence in the current mental health system of care in Sarasota County, and some were hesitant to even consider it a whole "system." It was widely noted that there are many silos of services and funding, and that such structuring is counterproductive to holistic care. A universal, or inclusive system of care would allow for better service coordination and data sharing. Many respondents pointed to ways that mental health services in the community are crisis-driven, which they saw as detrimental to intermediate services, not to mention prevention care, which many stakeholders saw as sorely missing from any strategic focuses on mental health, "The popularity of prevention and whether we get funding from the federal or state government waxes and wanes, depending on what's going on in the world. But prevention really should be something we always, always, always put resources into." There were many suggestions that mental health care should be part of an overall system of care that integrates medical and mental health care. Several respondents felt that the seclusion of mental health care from a broader system of health care led to a disproportionate care for mental illness.

Many stakeholders saw a significant need for more providers in general, but especially more child and youth psychiatrists or nurse practitioners who can prescribe psychotropic medications. One reason given for this is that Primary Care Providers (PCPs) frequently prescribe this medication to children and youth, yet they are not appropriately trained to do so, nor are they suited to proper ongoing monitoring. One provider who responded to the Primary Care Physician survey provides some insight into the challenges that come with trying to help young patients with mental health problems:

> It is unconscionable that insurance rarely covers even basic mental health services, and when they do, they pay our brilliant mental health professionals so poorly that they often can't afford to accept insurance. Try to find a well-trained, effective child/

> adolescent psychiatrist in Sarasota who accepts insurance. You can't! Every day I find myself wrestling with whether poor quality mental health services are better than none at all when faced with referring to those who are not effective but who accept insurance. And if the child is on a Medicaid plan...there's really nowhere to turn for quality care. As our resource coordinator, today alone I had conversations with 4 families: one who was concerned about their teen with the potential for immediate danger from self-harm or harming others; one with a 5-year-old in kindergarten who is being labeled the 'bad child' because of impulsivity and poor emotional regulation; a high school senior in a prep school who is severely depressed and anxious; and a teen who was seen in our office for the first time today and thinks about hurting herself about twice a week. If the families need to use insurance, we have almost no good options for these four patients. And if they live in certain geographic areas with limited ability to travel an hour for quality services, we hit another wall. And if the child has Autism too...well the wait list for a developmental evaluation and services is so long we lose months and even years before even getting an initial appointment.

Even while the two physicians who completed the PCP survey reported being knowledgeable about mental health resources and having established procedures for referrals, both physicians indicated that the current capacity of mental health providers in Sarasota County was insufficient to address the needs of children, youth, and young adults. There were some suggestions among stakeholders to have more psychiatrists who work in the public sphere and not for private agencies, though it was acknowledged that Medicaid does not have competitive reimbursement rates for psychiatrists, which is presumably why there are so few. One respondent said there was a need for more specializes psychiatrists, as with neuropsychiatry, and others stated that psychiatrists needed to be in more geographic locations so families do not have to travel long distances to find one. Some comments reflected a need for a youth treatment center that had multiple specialists, including therapists, psychiatrists, and nurse practitioners.

Not surprisingly, funding was an issue all interviewees had input on. There were many calls for increased funding, with many respondents pointing out the poor status of Florida's mental health care funding in recent years:

> We like to say at the state that we take mental health and substance abuse seriously, but then when we really look at the funding that's being provided we rank 49 through 50 at any given time in how much we're putting our money where our mouth is. You know? And so then what happens from there that filters down…and then determines what the rates are going be for all the providers. And so, you know, I just think that there's not enough money and it's going through a lot of hands to get down to the ground level folks.

There was wide agreement that mental health providers who worked in the public sphere were poorly compensated, and this was said to contribute to some of the inconsistency in care and turnover rates at agencies. Stakeholders saw inadequate funding as intertwined with many other systemic problems and said that, beyond a fundamental need for increased funding, there is a need to be more strategic in how funding is applied to system improvements. Some stakeholders pointed out the irony of being in a community with a lot of wealth, yet having such underfunded services. One interviewee commented that foundations were doing their part, but corporations should be contributing much more funding towards mental health services; after all, mental health providers are taking care of their workers and helping them sustain healthy workplaces.

Parent Interviews and Focus Groups

Methods

A total of twenty-seven parents and caregivers took part in interviews and focus groups. A combination of methods was used to talk with participants: three took part in in-person interviews, eight participated in phone interviews, and fifteen were a part of three separate focus groups. An interview/focus group protocol was developed to meet the needs of the objective (see Appendices H and I for the parent and youth protocol).

Recruitment flyers were widely distributed to mental health stakeholders and related youth-serving agencies and parent support groups in Sarasota County with the help of the Project Liaison. For in-person interviews and focus groups, a USF team member reviewed the study and ensured everyone understood the participant consent form. At the end of the interviews and focus groups, participants received $25 each. For phone interviews, the interviewee reviewed the study and gained consent to participate verbally, and interviews were recorded in order to transcribe them for analysis later. For any minors, a parent or guardian was asked to complete a parent permission form. The $25 participation incentive was mailed via certified mail to all phone-interview participants.

Analysis of the interviews was conducted using Atlas.ti, a qualitative data analysis software program. Several members of the evaluation team took part in coding interviews by theme and then using the output from that process to develop the report.

Findings

The data collection protocol for the parent interviews and focus groups explored their experiences with services including the domains of provider characteristics, accessing services, usefulness of services, respect for family values and culture, family strengths, family choice, sources of support, and service coordination. The findings below are organized by these domains.

Provider characteristics. One of the questions for parents was about the qualities of providers that were important to them. Two themes emerged regarding this question---engagement of both child and parent, and clinical expertise. Many respondents discussed the importance of providers being able to communicate effectively with their child/adolescent, "That he can make him feel comfortable when he's expressing his concerns." Another parent described what being "child friendly" means, "That is not just in the right field but in the right specialty because that's where their desire and their passion is, to help adolescents or to help a specific age group, and not just because there was a job opening." Participants also noted the value of providers who are able to communicate with them, using words such as respect, dignity, compassion, and "someone you can easily talk to without feeling judged." Parents also noted that these characteristics are crucial because of the often-difficult decisions to make regarding their child, such as whether and when to use medication, and placing a child in a residential treatment program.

The other theme is the skill level of the provider. These skills relate to helping children manage and deal with their behaviors, "That she identifies and develops a set of tools that she can use when she's triggered." Another parent described their child's experiences as follows, "I think they're positive, maybe a little bit challenging and maybe in a little bit of an uncomfortable way but not in a pressing way, just to get him to explore his feelings and look at dynamics between people. But it's very comfortable, you know, and at his pace." Another participant suggested that the need to have a specific goal as a provider helps clients move through the stages related to specific traumas. In addition to these themes, one respondent noted the importance of communication among providers, "Yes, and also the interactions between my child and the therapist and the psychiatrist and the primary doctor, too. All of those for the past four years have been wonderful."

Accessing services and service choices. Parents were also asked about any barriers to accessing services. The barrier to service initiation noted most often by parents was insurance (both commercial insurance and Medicaid). With Medicaid coverage, the challenge identified was finding providers that accept Medicaid. Parents with private insurance reportedly had easier access to services but noted that some private practices in Sarasota only accept a limited number of commercial insurance plans. Parents also discussed not knowing how or where to access services initially. "A lot of it is you don't know where to start. You don't know what resources are out there... and a lot of it is also finding the services that will take your health insurance because they, of course, don't advertise that, so you actually have to call around to a lot of places and get referrals." Even with insurance, some parents discussed how much out of pocket expenses there are.

> To get her diagnosed with ADHD cost me $120. And I have county insurance. It still was really expensive, because you have to pay the co-pay four separate times to see the doctor, because you can't do a visit with a kid to diagnose something like that in one visit.

Participants also discussed whether they were offered choices in the types of services they received. Responses were mixed; the perceptions of about half were that there were choices.

> Okay, so they will say, 'What days are best for you to bring him and what days are best for him to have an in-home...' They will just ask me, 'What's best for you?' as far as scheduling. Also, not the scheduling, but also where to do the therapy, in-home or in the clinic.

Other parents felt that there were few choices including both for scheduling visits and the location of services.

Once services were initiated, participants reported fewer barriers in continuing treatment. The challenges during treatment noted by several participants were turnover of therapists and a very limited number of psychiatrists. "And as far as psychiatrists, that's where we struggle. She has had four psychiatrists since we came down and we're actually getting switched to another psychiatrist." Two parents discussed keeping their children in treatment, even when they were ready for discharge, due to fear of "losing his spot."

Another barrier to accessing services described by participants is the lack of some types of services in Sarasota County. Among the parents interviewed, they identified the following services as not available in the county short-term inpatient care, residential treatment, an intensive step-down program after out-of-home treatment, and programs with expertise in gender-related services including for youth who are transgender. One parent explained this dilemma,

> It is this weird dialogue where I say, "she can't come home" and they agree. And then they say, "she can't stay here." And I am like, "Okay but, she can't come home so, what do we do?" And they say, "well, she can't stay here." So, no one was offering any solutions at all. I went to a lawyer who told me that my best bet was to give up my parental rights and have her placed in the foster system; which I just have not been able to bring myself to do.

In summary, parents described more challenges with service initiation than during treatment. The access issues identified include insurance coverage (both Medicaid and commercial insurance), a lack of information about how to find services, too few child psychiatrists, turnover among therapists, and service gaps.

Usefulness of services. When asked which services had been helpful, many parents named a particular type of counseling, such as play therapy or applied behavior analysis. Two parents noted the value of inpatient and residential treatment programs but both noted that neither of these settings are available in Sarasota County. The nearest inpatient program is in Orlando, and

the residential treatment program was reported to be out-of-state. Some parents discussed the importance of a mix of services such as counseling, occupational therapy, and speech therapy. When asked this question, some parents identified services that had been helpful for them such as a twelve-step program and programs that develop parenting coping skills. Two parents identified specified programs, the YMCA Shelter and Girls, Inc., as settings that were effective.

Some participants described the benefits of treatment for their child/adolescent.

> I'm grateful that she's gone [to services]. I notice on the days that it happens, there's insight. It may slip during the week. But I think that there has been insight into learning some things about herself. As evidenced by her, the space between triggers or acting out is longer and longer.

One participant described the pressure she experienced by the school regarding putting her son on medication for ADHD. "When he was five they really did not want him at school until I put him on medication." Another parent with a similar situation stated, "I don't think they should have to be on medication to be in school."

Service coordination. Participants were asked about whether services were coordinated. Responses were mixed to this question; about half of the parents felt that services were coordinated and some offered examples.

> Yes. He saw his pediatrician, who he comes to complaining about having headaches and joint pains, who referred him out to a couple different specialists to see about the medication that he is on now. So they are all working together to make sure that it's either something normal or he needs to have some testing done.

The perception of other parents was that services were not coordinated, especially when their child was receiving services from several provider agencies.

Use of family strengths and culture in treatment. During the interviews and focus groups, participants were asked to describe their family strengths and whether or not these strengths were used in treatment planning and implementation. Many parents were able to describe family strengths such as effective communication, doing things together, a flexible schedule, having a history of mental illness, being good listeners, not giving up, unconditional love, a sense of humor, and open discussion of issues. Many times these strengths were related to caring for their children:

> Well, we still care about her future. We have not really totally given up on her. I guess I consider it a strength that I was able to come to the decision that she was not safe at home. That's really, kind of, a hard thing to admit.

When asked whether professionals made use of family strengths in treatment planning, six participants responded affirmatively. However, all their responses focused on their involvement in treatment planning and care, rather than incorporation of family strengths. "They typically keep everyone in the loop, and make sure everybody's on board, and we review everything. It is a very open plan." A second parent noted, "she'll talk to him first and then she'll go, 'Okay, [Mom], we're done.' He will go in the room and go play and then she'll talk to me." The one exception is a parent who noted that her schedule is flexible; she described how the therapist knows and uses this flexibility when scheduling appointments. Three respondents noted that they are not included in treatment for their child. Two of the three respondents with older adolescents acknowledged that not being involved with their child's treatment made sense due to age; and both stated with confidence that the therapist would share information if risky behaviors were involved. Finally, almost all parents felt that their family values and culture were respected during treatment. Participants used terms such as respectful, attentiveness, and understanding to describe this aspect of treatment.

Sources of support. There was considerable variability in parents' responses regarding sources of support. The majority (n=10) described informal sources of support that they use for support including family members, friends, and coworkers. Two parents specifically discussed religion as a source of support, as explained by one parent,

> I rely a lot on God and people within the church. We have a big connection with just about everybody within the church and [my wife] sings for them and I'm trying to become a pastor so we just rely on each other, God, and trustworthy people that we can share with that aren't judging us.

Other parents identified professionals such as social workers, therapists, and school counselors as their sources of support. Two parents discussed networks of support, as one parent described,

> Right now I'm in different programs. Like I deal with the Pathways to a Better Life program. I am a board member for my son's school so I discuss issues that I am having, and these are the people that help me. So, I do have a support system.

One parent uses a Facebook support group for parents of children with special needs. When asked, other parents did not know of any support groups for parents for children with special needs and noted how helpful that could be. One parent noted that supports for youth who are LGBTQ and their family members are very limited in Sarasota.

Recommendations. Parent participants made the following recommendations about what would improve the system of care in Sarasota County:

- Insurance coverage. Improvements in insurance included better choices of specialists such as neurologists, more in-network providers, and reductions in co-pays.
- Availability of providers during a crisis rather than an after-hours answering service
- Addressing service gaps such as a transitional living program for older adolescents, inpatient and residential treatment programs in Sarasota county, and applied behavior analysts that are school-based
- More availability of psychiatrists and less turnover of therapists
- More flexibility in scheduling appointments by having providers who are open after 5pm and on weekends
- Care coordination especially for families with a child or adolescent with complex needs
- Supports for parents and caregivers. These supports could include parent support groups, one-on-one assistance from another parent, and a warm line.

Objective 5: Impact of Untreated Mental Illness

The purpose of Objective 5 is to evaluate the impact untreated mental health has on Sarasota County's economy, medical system, criminal justice system, families, schools and area businesses. To this end, three strategies were used to respond to this objective. First, we summarized available literature on the economic costs of untreated mental illness across multiple systems and sectors in the U.S and in Sarasota County, specifically. Second, the Sarasota County Mental Health Assessment Stakeholders Survey was used to assess stakeholders' perceptions of the impact of untreated mental illness. Lastly, a focus group was conducted with businesses in Sarasota County to get their feedback on how businesses are impacted by untreated mental illness.

The Economic Costs of Untreated Mental Illness in Sarasota County

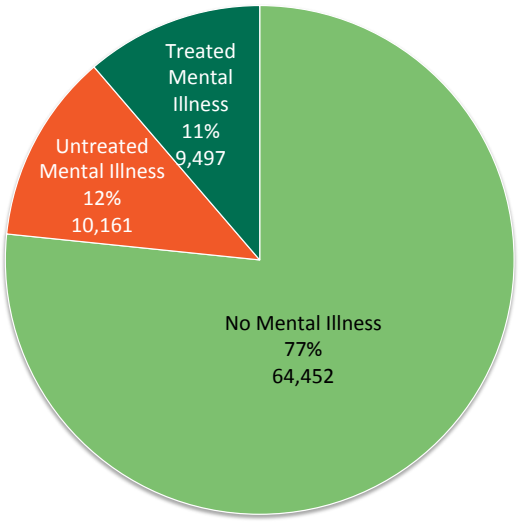
This report describes the development of an economic model to estimate the costs of untreated mental illness in Sarasota County for children, adolescents and young adults ages 0 to 24. Building upon the literature review, publicly available data along with data from peer-reviewed publications are used to estimate costs. The following sections describe the prevalence estimates used to generate economic costs for Sarasota County and define economic costs. These are followed by a description of how economic costs are measured for untreated childhood onset mental illness, and untreated young adult onset mental illness. This report follows the existing literature, which for childhood onset mental illness generally focuses on the economic costs associated with specific consequences of mental illness (justice involvement, suicide/self-harm, and educational outcomes) for children, and for adult onset mental illness focuses on the economic costs associated with specific behavioral health problems (schizophrenia, bipolar disorder, major depression, and substance abuse).

The Prevalence of Untreated Mental Illness

In Sarasota County Florida, the population of children and young adults in 2017 was 84,110, of which 66,987 were ages 0-19 and 17,123 were ages 20-24 (Source: https://factfinder.census.gov). The prevalence of mental illness among children in the U.S. is approximately 25% (Merikangas, Nakamura, & Kessler, 2009), while 17% of adults in Florida have a mental illness (http://www.mentalhealthamerica.net/issues/mental-health-america-prevalence-data). Thus, when applying these prevalence estimates to Sarasota County, 19,658 people ages 0-24 are expected to have a mental illness in Sarasota County during a year. Among youth ages 13-18 in the U.S., 11% have a mood disorder, 10% have a behavior or conduct disorder, and 8% have an anxiety disorder (https://www.nami.org/Learn-More/Fact-Sheet-Library). While data are not limited to young adults, 2.6% of all adults have bipolar disorder, 6.9% have major depression, and 18.1% have anxiety disorders (https://www.nami.org/Learn-More/Fact-Sheet-Library). Some adults have more than one diagnosis.

About half of the children and adolescents with a mental illness receive specialty treatment (Merikangas, Nakamura, & Kessler, 2009). According to Mental Health America, 61.4% of adults in Florida with a mental illness did not receive treatment (Mental Health America, 2017). Thus, there are an estimated 8,373 children and 1,787 young adults in Sarasota County with untreated mental illness. That amounts to 12.1% or about 1 in 8 children and young adults in Sarasota County. Figure 4 summarizes the breakdown between the general population, those with a mental illness who are treated, and those with a mental illness who are untreated.

Figure 4. The Prevalence on Mental Illness in Sarasota County among Children and Young Adults



What are Economic Costs?

Economic costs include the direct and indirect costs associated with a condition. The direct costs for untreated mental illness can be substantial. Such costs include the medical costs of treating an individual who attempts suicide, the cost of an involuntary examination for individuals who need to be Baker Acted for safety reasons, the cost of a psychiatric inpatient stay, the cost of incarcerating a youth with untreated mental illness who commits a violent crime, and more. However, the direct costs associated with untreated mental illness are small compared to the indirect costs. Indirect costs are sometimes referred to as the costs to society. For example, when a youth commits suicide, society loses all future productivity that youth would have contributed to society. One of the chief contributions for most adults is through their job. Economic costs include both the direct costs of the event (e.g., suicide) and the indirect or social costs (e.g., lost productivity).

In addition, the model developed in this report is based on a relationship between untreated mental illness and the immediate effects on one's life, and a relationship between untreated mental illness and future effects on one's life. While the relationship between untreated mental illness and current effects may be straightforward, several research findings also suggest a relationship between untreated mental illness during childhood and future effects.

1. The average time between onset of mental illness and treatment is 8-10 years for children (Wang, Berglund, Olfson, & Kessler, 2004). Thus, many children emotionally develop and mature during their adolescence while also dealing with an untreated mental illness.
2. Half of all adults with a chronic mental illness had an onset during childhood (NIMH, 2014). Thus, many adults with a mental health problem have been living with this problem since childhood.

Mental health treatment is very effective, especially when implemented early. According to the National Advisory Mental Health Council, the best treatments for serious mental illnesses today are highly effective; between 60% and 80% of individuals have significant reduction of

symptoms and improved quality of life with treatment. However, the large number of youth that are untreated, the long delay in providing treatment for those who are treated, and the fact that many children who develop mental health problems continue to have them into adulthood, suggests that some adverse outcomes during adulthood may have been avoidable if provided prompt and adequate mental health treatment as a child. The lack of treatment as a child is likely to place their life on a different trajectory compared to a child that received needed treatment (Child Mind Institute, 2015, 2016). The different trajectory can lead to negative outcomes, both today and in the future.

While 50% of all children with a mental illness are untreated, as noted earlier the economic costs associated with mental illness among children often focus on specific consequences of mental illness (e.g., juvenile commitment). Among youth with a mental illness who experience a negative consequence, the proportion untreated may differ from 50%. The following section explores the rate of untreated mental illness among children who experience a negative consequence for a lack of treatment.

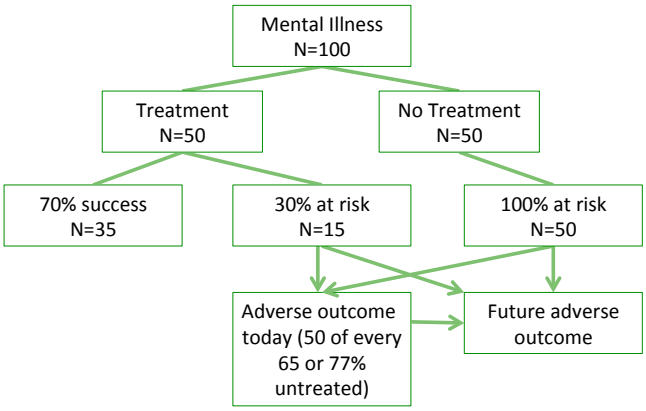
What Proportion of Youth with a Mental Illness Who Experience an Adverse Outcome Were Untreated?

A key question is what proportion of children who experience an adverse outcome are likely to have an untreated mental illness. In some cases, there are estimates specific to an adverse outcome. For other cases, we derive an estimate of the proportion with an untreated mental illness. Let us take the following example that estimates the proportion of youth with a mental illness in juvenile residential commitment programs who are untreated. If we have 100 youth with a mental illness, we would expect 50 are treated and 50 are not treated (Merikangas, Nakamura, & Kessler, 2009). Of the 50 who are treated, treatment will be effective for 60 to 80% (National Advisory Mental Health Council) and we assume their risk of juvenile justice involvement is very low (comparable to children without mental illness). Thus, if we assume that treatment is effective for 70% of children (the midpoint between 60 and 80%), then 30% of the 50 treated youth (approximately 15 children) are at risk for a significant adverse outcome. In addition, all 50 untreated youth are at risk for the adverse outcome. Thus, out of 65 youth who experience the adverse outcome, we would expect 15 to be 'treated' and 50 to be untreated. In other words, 77% who experience the adverse outcome (50/65) were untreated prior to arrest.

In addition to defining who was untreated, it is important to note that not all youth who are treated receive the right treatment or sufficient treatment. In some cases below (e.g., suicide) we consider the severity of the outcome to be sufficient evidence that treatment was inadequate and consider all youth with the negative outcome to be untreated.

Thus, as illustrated in Figure 5, children and young adults who have a mental illness and are untreated are at greater risk for adverse outcomes today. For every 100 children with a mental illness, 65 are at-risk for an adverse outcome, and 50 of the 65 are untreated. The figure also suggests a relationship between untreated mental illness and future outcomes. As noted above, children with an untreated mental illness may be on a different life trajectory. For example, once a child has an adverse event (e.g., justice involvement), the likelihood of future justice involvement is quite high. Thus, having an adverse event increases the risk of future adverse events. In addition, even if the child avoids an adverse event as a child, the lack of treatment can negatively affect the developmental path of the child, increasing the risk of adverse events in the future.

Figure 5. Children at-risk for adverse outcomes: An illustration of how lack of treatment affects the risk of an adverse outcome



The general formula used to calculate economic costs in this report follows the form:

Economic $cost_{2018}$ = [# people affected*(direct cost per person + indirect cost per person)]*CPI

Where direct costs equal the paid costs such as medical care for suicide attempts, and incarceration costs for people in prison. As described above, indirect costs are the costs to society, with lost productivity often the primary indirect cost. Whenever possible we use local data to determine the number of affected people. However, in some cases we must use national prevalence rates applied to the Sarasota County population. Similarly, costs are derived using Florida data when possible, but in some cases, national estimates of per person costs are used. Finally, published research is often several years old. In an effort to make cost estimates current, we use the Consumer Price Index (CPI) to update the costs to 2018 dollars. The following sections examine the economic costs associated with major consequences of untreated childhood onset mental illness including justice involvement, suicide, self-harm, and educational outcomes.

Economic Costs Associated with Justice Involvement

Over 70% of youth in juvenile justice settings have a diagnosable mental health condition (Shufelt & Cocozza, 2006). At least one quarter of all adults in the justice system also have mental health problems (James & Glaze, 2006; Reingle Gonzalez & Connell, 2014). Mental health problems in adults often emerge during adolescence suggesting that untreated mental illness among youth and young adults has consequences for justice involvement that last throughout adulthood.

Mental health problems among youth and young adults are associated with a greater risk of arrest, greater risk of juvenile detention, and greater risk of adult justice involvement. In Florida, youth entering the juvenile justice system may be placed into diversion programs, or if convicted, receive probation or be placed in juvenile residential commitment. Most youth arrested for crimes enter diversion programs or receive probation, not residential commitment programs. For example, in Sarasota County, Florida Department of Juvenile Justice (DJJ) reports that an average of 544 children were arrested per year between SFY 2012-13 and 2016-17, but only 38 youth per year were placed in juvenile commitment programs (data derived from http://www.djj.state.fl.us/research/reports/reports-and-data/interactive-data-reports/delinquency-profile/delinquency-profile-dashboard). Hyla (2016) found that the economic impact due to juvenile arrest was primarily due to its effect on educational outcomes. The economic costs associated with educational outcomes are addressed elsewhere in this report, and thus are excluded from the economic costs of justice involvement to avoid double counting. As a result, we focus on the economic costs associated with juvenile commitment.

Juvenile Commitment (Ages 0-18)

DJJ reports that an average of 38 youth per year entered juvenile commitment in Sarasota County between SFY 2012-13 and 2016-17. Seventy percent (27) are assumed to have a mental illness, and 77% (21) with a mental illness are assumed untreated. Thus, 54% of youth in juvenile commitment have an untreated mental illness (77% of 70%). The average direct cost per day for juvenile commitment in Florida is $151.80 (http://www.justicepolicy.org/uploads/justicepolicy/documents/sticker-shock-final-v2.pdf), and the average length of stay was 265 days (http://www.djj.state.fl.us/docs/car-reports/(2016-17-car)-residential-(final).pdf?sfvrsn=2). Thus, total direct costs for the 24 youth are $844,767 (in 2018$).

Similar to the case of suicide, the indirect costs from juvenile commitment are much larger than the direct costs. Research by McLaughlin et al. (2016) suggests there are $10 in social costs for every $1 of direct costs related to incarceration. Thus, there are $8,447,670 in indirect costs. Total economic costs associated with juvenile commitment are $9,905,737 (or $471,702 per child.

Youth released from juvenile commitment may be an important group to target in interventions. DJJ reports a 50% recidivism rate for youth released from commitment programs (defined as adjudication, adjudication withheld, or adult conviction for another crime within 12 months). The combination of mental illness and the potential for repeated contacts with the justice system create the potential for extremely high social costs.

Incarceration (Ages 24 and Younger)

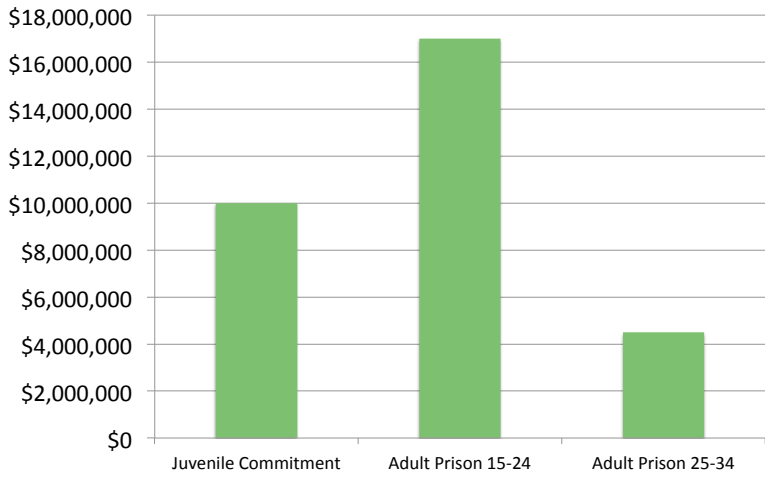
Some children transfer from the juvenile justice system to the adult justice system, and young adults ages 18-24 will be part of the adult justice system. The Florida Department of Corrections reports that 5,674 people statewide who are ages 24 or younger entered the prison system in SFY 2016-17. In order to estimate what proportion were from Sarasota County, we determined that Sarasota County had 1.45% of the state population ages 15-24. Thus, approximately 80 inmates entering the prison system are from Sarasota County. Of these 80, 26% (or 21 people) have a mental illness (Reingle Gonzalez & Connell, 2014), and 77% (16 people) were untreated. The average time served for a prison sentence is 4.6 years in Florida (the average sentence is 5.4 years, and on average inmates serve 85% of their sentence). Direct costs for prison in Florida were $20,367 per year in SFY 2016-17. Thus, direct costs for the 16 people for 4.6 years are $1,499,011 (in 2018$). Using the 10:1 ratio for social costs to direct costs, social costs are $14,990,110. Total economic costs are $16,489,123.

Future Incarceration due to Untreated Mental Illness (Ages 25-34)

In addition to increasing the risk of juvenile commitment, untreated mental illness among youth is associated with an increased risk of incarceration in adulthood. In order to estimate the costs associated with future incarceration as an adult aged 25-34, we first needed to estimate the number of incarcerated individuals in that age range from Sarasota County. The Florida Department of Corrections reports that 10,417 people ages 25-34 entered the prison system in SFY 2016-17. In order to estimate what proportion were from Sarasota County, we determined that Sarasota County had 1.26% of the state population ages 25-34. Thus, approximately 132 inmates entering the prison system each year are from Sarasota County. Of these 132, 26% (or 34 people) have a mental illness (Reingle Gonzalez & Connell, 2014), with half starting during childhood (17 people), and 77% of the 17 (13 people) untreated. Finally, we assume that 1/3 of these people (4) had not been incarcerated between the ages of 0 and 24 (five year recidivism rates in Florida are 66% and their costs are already included above). The average time served for a prison sentence is 4.6 years in Florida. As noted above, annual direct costs to house an inmate in Florida are $20,367, and social costs are 10 times larger than direct costs for incarcerated adults. Thus, total economic costs (converted to 2018 dollars) for the four inmates are $4,740,623.

Figure 6 presents the economic costs for criminal activity due to untreated mental illness in children and young adults. Total economic costs (in 2018 $) are $31,795,049.

Figure 6. Economic Costs Associated with Juvenile Commitment and Adult Incarceration



Economics Costs Associated with Suicide and Self-Harm

One of the most important consequences of untreated mental illness is a suicide. According to the Centers for Disease Control (CDC), suicide is the third leading cause of death among persons aged 10-14 (CDC, 2017). Sarasota County reports an average of six suicides per year between 2013 and 2017 among individuals ages 0-24 (Florida Health CHARTS, DOH, 2018), with most occurring among adults ages 19-24. Evidence suggests that 60% of adolescents and 90% of adults who completed suicide had a mental illness (Brent at al., 1999; Shaffer & Craft, 1999). This results in a weighted average of 83% of suicides being associated with mental illness in Sarasota County. Thus, five of the six suicides in a year are attributable to mental illness. While one or more people who completed suicide may have received mental health treatment, it is quite likely that all were undertreated. Under treatment of mental illness is common with some research estimating that nearly half of all people who receive mental health treatment do not receive adequate treatment (Harvey & Gumport, 2015). The severity of the outcome suggests that none of the five individuals received adequate treatment, and thus all five are included in the economic cost. Research has found that the average economic cost in the U.S. for a suicide by someone who is age 15-24 is $2,012,476 (Shepard, Gurewich, Lwin, Reed, & Silverman, 2016). The majority of the economic cost is comprised of foregone earnings. Thus, the total economic cost for suicides among young people is over $10 million per year (in 2018).

As discussed above, the high rate of untreated mental illness can have implications for suicides in the future. Treating the illness today may help the person with alleviating the problem, or provide the necessary coping skills for people to avoid taking their own life in the future. Thus, we examined the number of suicides in Sarasota County for individuals 25-34 for the years 2013 through 2017. There was an average of eight suicides per year. Seven had a mental illness if we assume that 90% of adult suicide victims had a mental illness. Of these, if 50% had a childhood onset of mental illness, then four had an onset during childhood. If 77% were untreated, then three of the four were untreated. Thus, the economic cost due to future suicides associated with untreated mental illness is $6,544,572 (in 2018).

In addition to completed suicides, mental illness is also associated with the infliction of self-harm. Sarasota County data indicates that 92 people ages 10-24 were hospitalized for self-inflicted injuries between 2013 and 2015, or 31 per year (Florida Health CHARTS, DOH, 2018). Suicide and self-harm share the same risk factors (Nock, Joiner, Gordon,

Lloyd-Richardson, & Prinstein, 2006), thus we also assume that 83% who self-harm have an underlying mental illness. Again, assuming that 77% of those with a mental illness were untreated would imply that 20 have an untreated mental illness. The average economic cost is $34,553 per hospitalization due to non-fatal self-harm (Florence, Haegerich, Simon, Zhou, & Luo, 2015). Thus, the economic cost for hospitalizations among this age group for self-harm in Sarasota County is $749,109 per year (in 2018).

Not all cases of self-harm result in hospitalization. An average of 65 people ages 10-24 were treated in emergency rooms without the need for an inpatient stay between 2013 and 2015 in Sarasota County. Again, assuming that 83% were associated with mental illness and 77% of those with mental illness were untreated suggests that 42 had an untreated diagnosable mental health condition. The average economic cost in the U.S. is $4,465 per case suggesting that the total economic cost is $203,283 per year (in 2018$).

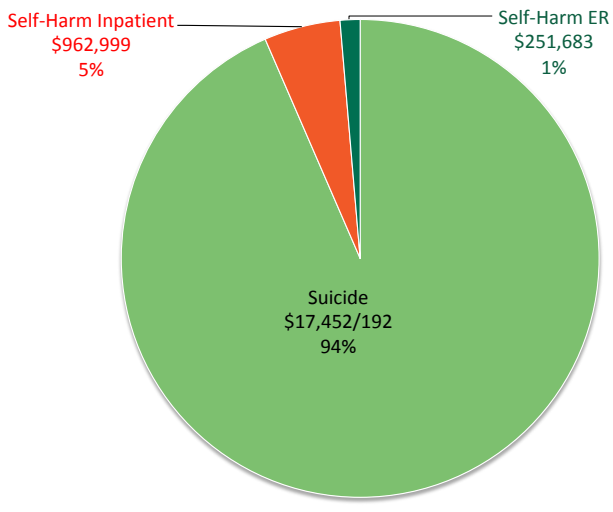
Self-harm is a particularly important signal of need for treatment intervention. Among those with a history of non-fatal self-harm, 70% have attempted suicide at least once (Nock et al. 2006). Research has found that 1.6% of cases of non-fatal self-harm led to a completed suicide within 12 months, and 3.9% within five years (Carroll, Metclaf, & Gunnell, 2014). While these percentages may seem small, a prior attempt is one of the more important predictors of a completed suicide. Thus, of the 96 people that received inpatient or emergency room care for self-harm, 3-4 will likely commit suicide within five years (3.9% of 96). Intervention among children and young adults that receive inpatient or emergency room care for self-harm may prevent future suicide attempts and completed suicides.

Programs may be developed in cooperation with local hospitals to increase follow-up efforts with parents and youth after hospital treatment for intentional self-harm. A hospital-based program could balance the need to provide additional encouragement and information to parents to make sure youth receive needed help with requirements for patient confidentiality.

Given the large difference in economic costs between completed and attempted suicides, it is also important to mention factors related to the lethality of attempts. By far, the method of suicide associated with the greatest lethality is firearms (http://lostallhope.com/suicide-methods/statistics-most-lethal-methods). Approximately 90% of suicide attempts by firearm are fatal. Suffocation (e.g., hanging) is also highly lethal. In contrast, poisoning (e.g., overdose by prescription and non-prescription drugs) and cutting (e.g., wrists) have much lower rates of lethality.

Figure 7 summarizes the $18.4 million in economic costs associated with suicide and self-harm among children and young adults in Sarasota County, with $17.4 million in costs associated with suicide, $749 thousand in costs associated with self-harm that resulted in hospitalization, and $203 thousand in costs associated with self-harm that was treated in the ER.

Figure 7. Economic Costs of Suicide and Self-Harm



Economic Costs Associated with Educational Outcomes – High School and College Dropouts

Mental illness is associated with several negative educational outcomes including absenteeism, disciplinary problems, and dropping out of school. Youth and adolescents with untreated mental health conditions are at risk of poor academic performance and dropping out of school, and they are more likely to be involved in the juvenile justice system (Stagman & Cooper, 2010). The inability to effectively curb externalizing behaviors may lead to children and youth acting out in school. Due to strictly enforced zero-tolerance policies, particularly with ethnic and racial minorities, such policies promote the "school to prison pipeline" (Cass, Curry, & Liss, 2007). Here, we focus on the costs associated with dropping out of school due to the large difference in economic outcomes for youth who do and do not graduate from high school.

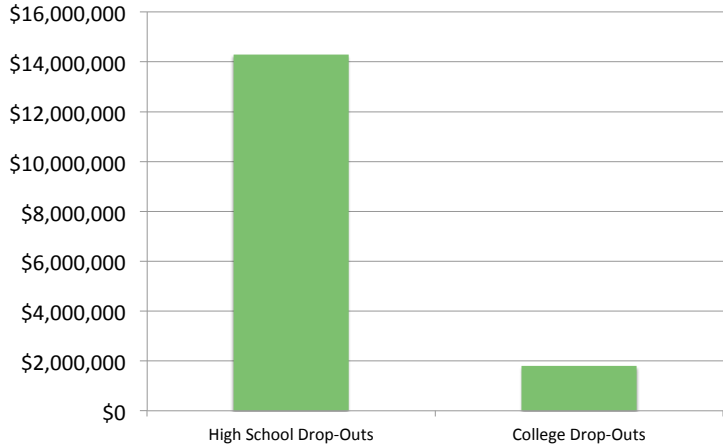
Sarasota County has a high school graduation rate of 85.7% (http://www.fldoe.org/core/fileparse.php/7584/urlt/GradRates1617.pdf), and graduated 2,700 students in 2018 (https://www.gainesville.com/news/20180519/class-of-2018-dismissed-in-sarasota-county). This suggests that 450 students did not complete high school (2700/.857-2700). However, most of the 450 did not drop out of school. The majority of non-completers remain enrolled and presumably, most will graduate. Sarasota County's dropout rate was 3.6% in 2016-2017 (http://www.fldoe.org/core/fileparse.php/7584/urlt/CohortDropoutRate1617.pdf). Thus, of the 450 students, 113 dropped out (3.6% of 3,150) and the remaining 337 were non-completers. If we assume that 10% of non-completers (or 33 students) will not graduate, then 146 students drop out of school each year. Research has found that 31% of students not completing high school have a mental illness (Maynard, Salas-Wright & Vaughn, 2015), suggesting that 46 students that do not complete high school in Sarasota County have a mental illness. Maynard, Salas-Wright and Vaughn (2015) also found that 63% of dropouts who reported mental health problems did not receive mental health treatment. Assuming that 63% of the 46 students in Sarasota County did not receive treatment, 29 of the 46 students were untreated. Overall, 20% of high-school drop-outs have an untreated mental illness (63% of 31% of high school drop-outs with mental illness). The economic costs to not completing high school were $506,958 per student (Belfield, 2014 updated to 2018 dollars). Earnings differences between high school graduates and people who did not complete high school produce the substantial costs. Thus, the economic cost for untreated mental illness in terms of high school graduation are $14,701,771 (in 2018 dollars) per year.

Even if young adults graduate from high school, the current economy often requires a college diploma for many jobs. As a result, more high school graduates are going to college, including those with mental health issues. However, college can be an extremely stressful time for students with a mental health problem. The Healthy Bodies Study found that 34% of college students have a history of mental illness and over half of the students with positive depression and anxiety screens while in college did not receive treatment (Eisenberg & Ketchen Lipson, 2017). Their research also found that dropout rates are twice as high for students with mental illness. Indeed, providing services to 100 students with depression may prevent six students from dropping out of college (Healthy Minds Institute, 2013).

Thus, of the 2,700 high school students that did graduate, approximately 25% (or 675) are likely to have some mental health problem. About 70% of high school graduates go on to college, but we anticipate this number is lower for graduates with mental illness. Given that the Healthy Bodies project found 34% of students had a history of mental illness, we estimate that 230 high school graduates in Sarasota County with a mental illness go on to college. Half of students in college with mental illness are not receiving treatment, leaving 115 students are untreated. Thus, we anticipate that 6% of the 115, or 7 students would graduate from college if they received adequate mental health treatment. The social benefit of retaining the student is estimated to be $213,200 per student (Healthy Minds Institute, 2013), for a total of $1,590,898.

Figure 8 summarizes the economic costs in terms of educational outcomes. Total economic costs for Sarasota County are $16.3 million per year.

Figure 8. Economic Costs Associated with Educational Outcomes



Economic Costs Associated with Lost Productivity – Young Adult onset Mental Illness

It was stated that an estimated 50% of childhood mental health disorders persist into adulthood when left untreated (Hofstra, Van der, & Verhulst, 2000). There is evidence that untreated mental illness impacts the economy due to the tendency for youth and adolescents to have poor school performance, leave school early, and be unemployed (Committee on School Health, 2004; McDermott and Carter, 1995).

While some individuals ages 18-24 are in college, others enter the labor force. Considerable research suggests that mental illness has significant effects on worker outcomes, including higher unemployment and lower wages. The largest impact of mental illness for young adults is lost productivity. Mental illness can limit the ability of an individual to be gainfully employed, and even when employed have higher turnover and greater absenteeism due to their illness.

While much of the research involving mental illness in children focuses on specific outcomes (e.g., justice involvement and education), there is considerable research on adults that focuses on the economic consequences of specific diagnoses. We focus on four diagnoses that have high onset rates among young adults: schizophrenia, bipolar, major depression, and substance abuse. Other diagnoses (e.g., anxiety disorders) have a high prevalence among young adults, but tend to onset during childhood. The costs associated with child onset diagnoses should be included in the economic costs to suicide, justice involvement, and educational outcomes described above. In addition, even for the specific diagnoses examined, we focus on the cost to society in terms of lost employment and exclude costs associated with suicide and incarceration discussed earlier.

Schizophrenia

About 1% of the adult population has schizophrenia. However, many individuals do not have onset of the disease until after 24. Thus, we assumed conservatively that 30% of the cases onset between 20 and 24, and that 40% of new onset cases go untreated in a given year (https://www.treatmentadvocacycenter.org/evidence-and-research/learn-more-about/25-schizophrenia-fact-sheet). Thus, of the 33,839 adults ages 20-24 in Sarasota County, we anticipate that 45 have untreated schizophrenia in a given year. With per person social costs of $33,500 (derived from Clouteri et al., 2016), total economic costs (updated to 2018 dollars) are $1,605,488.

Bipolar Disorder

About 2.6% of the adult population has bipolar disorder. We assumed that 30% of adults with bipolar have an onset between ages 20 and 24, and half of the population with bipolar disorder

are untreated in a given year (https://www.treatmentadvocacycenter.org/evidence-and-research/learn-more-about/463-bipolar-disorder-fact-sheet). Thus, of the 33,839 adults ages 20-24 in Sarasota County, we anticipate that 180 have untreated bipolar disorder to a given year. With per person social costs of $11,724 (Wyatt & Henter, 1995; Dilsaver, 2011), total economic costs (in 2018 $) are $2,443,895 per year.

Major Depressive Disorder

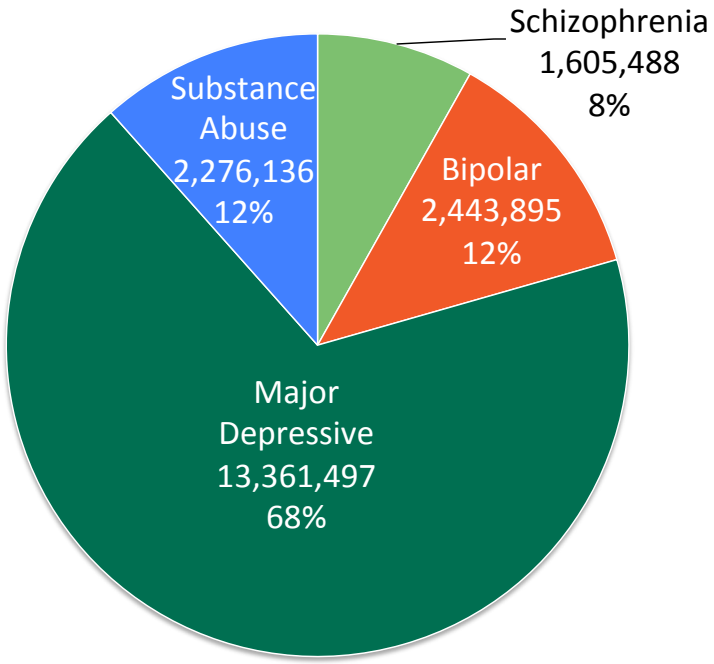
Major depression is more common than schizophrenia or bipolar disorder, with the NIMH reporting that 11% of individuals ages 20-24 have an onset of major depressive disorder (https://www.nimh.nih.gov/health/statistics/major-depression.shtml). Fifty percent are likely to be untreated (Gonzalez, 2010), suggesting that 1,861 people ages 20-24 have untreated major depressive disorder. At an average social cost of $6,623 (Greenberg, Fournier, Sisitsky, Pike, & Kessler, 2015), total economic costs (in 2018 $) are $13,361,497.

Substance Abuse

Lastly, substance abuse has important implications for workers and employers. Nearly 8% of workers have an untreated substance abuse problem (https://www.drugabuse.gov/publications/drugfacts/nationwide-trends). However, the onset of substance abuse problems often occurs during adolescence. Such costs would be included above. About 25% of substance use disorders have an early adult onset, implying that 2% of workers have an early adult onset. In addition, there is a high rate of comorbidity between substance abuse and the mental health problems already included. Estimated comorbidity rates are about 50% (https://www.drugabuse.gov/publications/drugfacts/comorbidity-substance-use-disorders-other-mental-illnesses). Thus, 1% have an adult-onset untreated substance abuse problem without a mental illness. Average economic costs are $6,643 (Goplerud, Hodge, & Benham, 2017) for a total of $2,276,136 (in 2018 $).

Thus, total economic costs for young adults in terms of lost productivity are in Figure 9. The economic costs associated with adult-onset untreated mental illness are $19.7 million per year.

Figure 9. The Economics Costs of Untreated Mental Illness for Young Adults



Other Issues – Medical Care and Child Welfare

The analysis of economic costs focused on four areas, suicide, justice involvement, education, and young adult productivity outcomes. There are additional outcomes that may be relevant but research is inconclusive about the effects. For example, people with mental illness often have high rates of physical health problems. However, it is not clear that treating the mental health condition will necessarily reduce physical health care costs. One way for this to occur is if providing mental health treatment will avoid high cost hospitalizations due to untreated physical health conditions. However, some research has found that providing community mental health treatment actually increased the use of hospital care. The more people contact the healthcare system, the more care they tend to use. The higher costs are not necessarily a negative and may even have positive implications. However, it is difficult to disentangle these effects and thus we chose not to include this mechanism in the computation of economic costs.

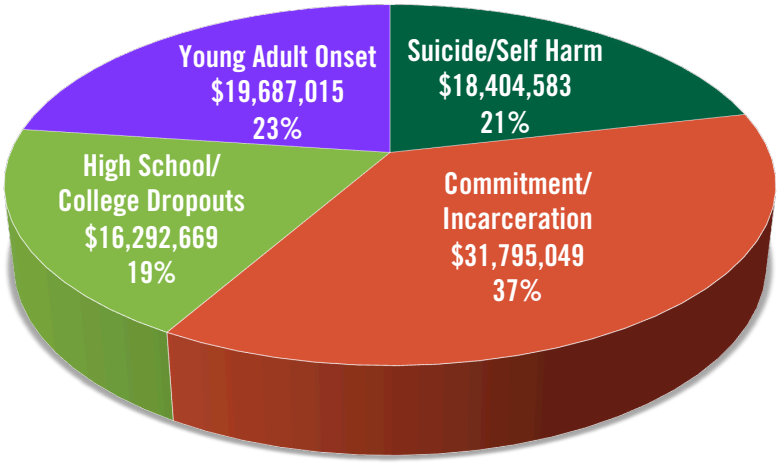
One additional target group that merits discussion is children involved in the child welfare system. Schneiderman and Villagrana (2010) provided a synopsis of the many consequences of untreated mental health problems specifically among children and youth served by the child welfare system. When left untreated, trauma experienced by children and youth has the potential to result in post-traumatic stress, sleep disturbances, disordered eating, suicidal ideation, anxiety, depression, and other psychiatric problems (Dallam, 2001; Mullen, Martin, Anderson, Romans, & Herbison, 1996; Silverman, Reinherz, & Giaconia, 1996). Half of children in child welfare have a diagnosable mental health condition (Burns et al., 2004). Clearly, it would be inappropriate to blame the child or their health for the need for child protection to be involved. The computation of economic costs for children focused on adverse outcomes (suicide, justice involvement, and education). However, for children in the child welfare system, treating their mental illness would probably not prevent the adverse outcome of child maltreatment (it may help to prevent the adverse outcomes already incorporated into report). In addition, the Medicaid program is responsible for the mental health treatment of children receiving out-of-home child welfare services. However, children and families exiting the child welfare system may remain vulnerable, as evidenced by the fact that 8% of families re-enter child welfare in Sarasota County within 12 months after reunification. Parental substance abuse and mental health problems are also extremely common among families in child welfare with 30% of parents having an untreated substance abuse or mental health problem. Thus, there may be opportunities to provide new programs or enhance existing programs geared towards the behavioral health (both mental health and substance abuse) of parents and children in an effort to reduce future maltreatment and re-entry into the child welfare system.

Total costs and Implications

Figure 10 illustrates the $86,179,317 per year in economic costs due to untreated mental illness for children and young adults in Sarasota County. The costs to society are very large because children not treated often fail to contribute fully to society for their entire adult life. Far too many do not complete school, others spend many years behind bars, and others end their life before reaching adulthood.

Figure 10. The Economic Costs of Untreated Mental Illness

A Breakdown of the $86,179,317 in Economic Costs Due to Untreated Mental Illness for Children and Young Adults in Sarasota County



We feel that the costs, while substantial, are a conservative estimate of the social costs. The four major categories considered (suicide, criminal justice, education, and worker productivity) are primary drivers of social costs. However, there are many other ways that untreated mental health problems can affect quality of life. In addition, even among the outcomes considered, medical claims likely underreport self-harm; even if a student graduates from school, mental health can adversely affect grades limiting future opportunities; and about 15 children are arrested for every child that enters juvenile commitment.

While the economic costs to society are very large, it is important to note that not all of these costs are avoidable. In some cases, the best mental health treatment will not change the outcome. However, as noted earlier, between 60% and 80% of individuals have significant reduction of symptoms and improved quality of life with a combination of pharmacological and psychosocial treatments and supports. Thus, the potential for substantial benefits exists.

The beginning of this section of the report suggested that over 10,000 children and young adults in Sarasota County have an untreated mental illness. It may be challenging to reach all children and young adults with a mental health problem. However, there are opportunities to target efforts towards children at the greatest risk. For example, those who have already self-harmed, been involved with the justice system, struggling in school, or involved in the child welfare system may be at particularly high risk of adverse outcomes.

Comparisons to national estimates of the economic costs are challenging because national estimates of the economic costs associated with mental illness and untreated mental illness vary widely. As is the case with the estimates in this report, small changes in the assumptions can have important effects on the estimates. For example, Insel (2008) estimated the cost of serious mental illness to be $200 billion per year, or approximately $721 per person in the U.S. (converting the costs to 2018 dollars and dividing by the current population of 325 million) The estimated costs in this report, $86 million, equal $1,024 per child and young adult in Sarasota County. There have been few efforts to estimate the costs of untreated mental illness for specific regions. The HSM Group developed a model to estimate the costs of untreated mental illness among adults in the Kansas City metropolitan area (HSM Group, 2012). They estimated there were 94,478 cases of untreated mental illness costing $624 million in 2012, or $7,266 per

person in 2018 dollars. For Sarasota County, our estimate for 10,161 children and young adults was $86 million or $8,482 per person. In both the comparison to national estimates and the comparison to Kansas City, the higher per person cost for Sarasota County reflects the younger age group in this analysis.

Impact of Untreated Mental Illness: Findings from the Sarasota County Mental Health Assessment Stakeholders Survey

The Sarasota County Mental Health Assessment Stakeholders Survey was also used to assess respondents' perceptions regarding the impact of untreated mental illness. Respondents were asked to rate the extent to which they felt various consequences were associated with child and youth untreated mental illness in Sarasota County. The consequences included in the survey were informed by a literature review on the impact of untreated mental illness across various systems. Again, items for this domain were rated on a Likert scale from 1 to 5, with higher ratings indicating greater perception that the items were associated with untreated mental illness. As shown in Table 12, for all items, participants indicated each of the consequences were associated with untreated mental illness to a "great extent" or "very great extent." Largely, participants agreed that untreated mental illness led to behavioral disruptions in school ($\bar{x}$ = 4.68), health risk behaviors such as alcohol and drug use ($\bar{x}$ = 4.65), and overcrowding in jails and prisons ($\bar{x}$ = 4.46). To a lesser degree, participants indicated absentee-ism from work and/or school and physical health disparities were a consequence of untreated mental illness.

Table 12: Perceived Consequences of Untreated Mental Illness

Consequence		Min.	Max.	Mean (SD)
Behavioral Disruptions in School	(n=41)	3	5	4.68 (.52)
Health Risk Behaviors	(n=40)	2	5	4.65 (.66)
Overcrowding in jails and prisons	(n=39)	1	5	4.46 (.88)
Child Abuse and Neglect	(n=41)	2	5	4.39 (.86)
Baker Act Examinations	(n=40)	2	5	4.38 (.81)
Homelessness	(n=41)	2	5	4.32 (.82)
Income Disparities	(n=40)	2	5	4.28 (.96)
Absentee-ism from School or Work	(n=40)	1	5	4.23 (1.03)
Physical Health Disparities	(n=39)	2	5	4.13 (.92)

In an open-ended question asking respondents to identify other impacts of untreated mental illness that they noticed in Sarasota County, the following additional consequences were stated:

- Adoption trauma
- Increased drop-outs or declining higher level courses in school
- Impacts on family members including siblings
- Increased costs for emergency room visits, law enforcement, and court
- Unemployment and/or reduced employment opportunities
- Costs related to ineffective treatments for related or unrelated symptoms

Particularly regarding increased costs of medically ineffective and inappropriate treatment, one respondent added the lack of appropriate resources to screen and treat individuals coupled with a lack of provider knowledge and duplicating treatments "wastes tens to hundreds of thousands of dollars per year, at minimum." The financial challenges of housing persons with untreated mental illnesses leads to increased incarcerations as a means to "temporarily warehouse" affected individuals which fails to benefit that person or the community.

Perhaps, this statement offered by a survey participants sums it up best, "We, as a society, need to start taking untreated mental health very seriously. We, as a society, need to treat mental health as seriously as we would treat high blood pressure or diabetes. It needs to be considered as important as seeing your primary care physician. Mental health has been ignored for too long in our society and we are seeing first-hand the problems this has been causing with just a few of those listed above."

Impact of Untreated Mental Illness: Findings from a Sarasota County Businesses Focus Group

Two individuals from business in Sarasota County participated in the business member's focus group. Both individuals reported that their employers offered health insurance for full time employees. It was reported that an employee health and well-being program was offered through one employer, and that the program was initiated by the Human Resources office at the company. One participant described an incident where an employee was experiencing mental health issues that escalating over a period of time. The company supported and worked with the family of the employee:

> [The company was] recognizing that the individual was struggling, and that we really needed to make sure that the family understood what was going on, and what resources were available and how we could access them. And actually making those calls, making those warm transfers, making those connections for the family to kind of ease their burden.

Both participants indicated that they felt there was a stigma in a business environment where employees do not feel comfortable in asking for assistance with mental health issues for themselves or family members.

Effects of Mental Illness on Businesses

Participants felt that mental health concerns were often misdiagnosed and misrepresented as a substance use disorder if the employee is abusing substances. Participants felt that undiagnosed mental illness can lead to absenteeism, loss of productivity, potential homelessness, and having children placed in foster care. Participants reported that assisting an employee with mental health concerns should be dependent on the situation. It was brought up that assisting part time employees ineligible for insurance benefits is a barrier:

> One of the barriers was that she was part-time, so she was not benefits-receiving. And she took a leave of absence, and because we have in-house counselors, that's how we addressed it initially, but it was hard to get her services because it was hard to get a diagnosis on her.

Recommendations

Participants reported that there needs to be more accessible information regarding mental health for employers and employees, that there should be advocacy services that employees can call, and that more businesses should look into telehealth services. Another recommendation was that there needs to be a more enhanced continuum of care for young children, and that there needs to be more services for the 18-24 year old population. It was mentioned that there was a significant gap in the service array for 18-24 year-olds.

Objective 6: National Benchmarks

This objective consists of a review of the literature on behavioral health benchmarks for potential inclusion to enhance the mental health domains and to ensure that all the populations of interest, in this case residents 0-24 years of age, are a focus of Sarasota County's existing Scorecards. It is also informed by stakeholder interviews that indicate a need for a focus on prevention and early intervention, access to healthcare, trauma-informed care, and engagement in services.

The *Crossing the Quality Chasm* report (Institutes of Medicine, 2006) considered a framework for measuring outcomes first proposed for primary healthcare (Institutes of Medicine, 2001) and applied it to behavioral health. This framework includes six domains: effectiveness, efficiency, equitability, safety, timeliness, and patient/community centeredness. It notes that fewer clinical administrative data bases exist than in primary care and that quality measurement is less developed than in primary care. In part this is due to having multiple disciplines and stakeholders involved in care and treatment with different metrics. This may also be due to the differing profiles or consumers served in the public sector as compared to those served in the private sector, with those served in the public sector having more severe and chronic disabilities. The report resulted in recommendations to identify and/or refine quality measures, require that these be reported to a single repository, ensure these measures are displayed in ways that are useful to multiple audiences, and establish models for generating benchmarks.

In the intervening time, efforts have been made to implement these recommendations (see, for example, Herbstman & Pincus, 2009; Kilbourne, Keyser & Pincus, 2010). However, these efforts are disjointed, with no single entity responsible for implementing the recommendations, with the result that there is still a lag in indicator development, testing, and refinement; no entity responsible for promoting best practices; and limitations in the data infrastructure. A recent review asserts behavioral health care quality measures still lag behind primary care and that there still has been limited movement towards an actionable quality measurement system that allows for performance and outcome monitoring and quality improvement (Kilbourne, Beck, Spaeth-Rublee, Ramanuj, O'Brien, Tomaysu et al, 2018). Internationally, examples of widespread use of benchmarks include the United Kingdom's Benchmarking Network that was created to shore up perceived insufficiencies in national behavioral health data collection and to best use the large amount of data that is collected. In the US, best practices come from the Department of Veteran's Affairs and pay-for-performance models that force adoption of quality measures because providers are paid for improvement in outcomes.

The literature suggests that there is no quick fix towards implementing reliable, valid, and feasible quality measures, mental health scorecards, and benchmarks. A review of scorecards found few with benchmarks, and those that did include benchmarks had a narrow focus and included only a few indicators and were limited in the scope of the population addressed. Only scorecards with mental health indicators were considered, and the Crossing the Quality Chasm aims listed above were used in the review of potential measures to enhance the existing Sarasota Scorecards. The measures below were in the final review.

In Table 13, the first example of scorecards that uses mental health benchmarks is a national scorecard developed using measures identified by the Commonwealth Foundation and uses thirteen indicators to address the six aims of health outcomes, quality of care, efficiency, and equity. The equity aim is addressed through analyses by race and ethnicity and for vulnerable groups, and it includes indicators associated with risk for mental health disorders, such as health insurance. To use this as a model, data sources that would address adult and child populations would have to be identified. But it is succinct, uses administrative data, and is replicable.

Mental Health America produces an annual ranking of states on mental health indicators, both adult and child. It does not have benchmarks associated with the rankings. Although it doesn't address the aims of the *Crossing the Quality Chasm* report (2001), it does have a measure of workforce availability that is related to mental health care access. However, it is a measure that Sarasota County already reports in its Scorecard.

Medicaid also publishes state health performance indicators that includes its Health plan/ Employer Data Information System (HEDIS) measures, such as follow-ups after a mental health hospitalization, concomitant prescriptions for antipsychotics, percent of children prescribed medications for ADHD with at least two follow-up visits, and developmental screenings for children ages 0-3. Like the Mental Health America report, it does not include benchmarks, but there are rankings and comparisons to other states. HEDIS measures, where accessible, would address quality domains (Lauriks, Buster, deWit, Onyebuchi, & Klazinga 2012).

The Robert Wood Johnson Foundation publishes County Health Rankings that include health behaviors, clinical care (including access and quality of care), social and economic factors, and the physical environment. The data sources are broad and include the Behavioral Risk Factor Surveillance System, the American Community Survey, and other surveys from the Census, the Centers for Disease Control, the US Department of Housing and Urban Development, the Centers for Medicaid and Medicare Services, and Map the Meal Gap. The County Health Rankings do address equity and present data by race and ethnicity. The measures included do not address child and adult indicators equally because of the administrative data sources. Again, while this is not entitled a score card *per se* and it doesn't provide benchmarks, it does provide z-scores that allow counties to compare themselves to the average score.

The Agency for Healthcare Research and Quality (AHRQ) reports adult and child measures of quality treatment. AHRQ does present benchmarks for one mental health indicator: suicide deaths for those ages 12 and older. The benchmarks are derived from top performing states. It provides estimates, but no benchmarks for adults and children with major depressive episodes ages 12 and older. The measures are limited in that they don't address all of the aims of the *Crossing the Quality Chasm*, nor do they address the entire population of interest to Sarasota County in this report, those aged 0-24.

Using the National Inventory of Mental Health Quality Measures, Richard Herman and colleagues reviewed over 300 measures and reduced the list to 56 measures that rely on administrative data, i.e., those data that are already collected for other purposes, such as billing (Hermann, Chan, Chiu & Provost, no date). These measures fall into seven domains of quality: treatment, access, continuity, coordination, prevention, safety and assessment. Like AHRQ measures, benchmarks were established based on the performance of the top ten percent of providers adjusted for the number of patients per provider. Though dated, this approach has advantages in that it relies on administrative data which keeps the user burden low, has a sound mathematical basis, is reasonably objective, and has a replicable methodology.

Table 13: Scorecards that Include Benchmarks Related to Mental Health

Organization	Mental Health indicators	Benchmark	Associated indicators	Benchmark
Schoen et al (2010) using data compiled by the Commonwealth Foundation	Adults limited in activities due to physical, mental or emotional problems (%);	11.5%	Health insurance coverage Adult	100%
	Children missing 11 or more days of school due to illness or injury	3.8%	Adults without problems getting care dues to costs	91%
	Needed MH care and received it Adults Children	80% 80%	ER visits that are preventable or could have been addressed in less restrictive settings (HEDIS)	6%
AHRQ / NHQDR	Suicide deaths among persons age 12 and over per 100,000 population	9.38		

To summarize the review of these measures and methods, the adult measures did not differentiate between the needs of those in the 18-24-year-old group and older adults. Child measures similarly were narrowly focused on one or two indicators, and because of the limitations of administrative data, were limited in age range to older children and adolescents. Finally, the measures reviewedagain because of the constraints of administrative datadid not tend to address the quality aims as described in the aims of the Crossing the Quality Chasm report. (See Table 13.)

To start to address the need for actionable data, use of the Health plan/Employer Data Information System (HEDIS) behavioral health measures is recommended because they are used broadly by public, i.e., Medicaid and Medicare, as well as private payors (National Committee for Quality Assurance, no date). These measures address effectiveness of care, access and availability of care, and utilization. The specific behavioral health measures for effectiveness are listed in Appendix D. They address management of depression, attention deficit disorders, follow-ups after hospitalization or emergency room visits for mental health, and management of schizophrenia and bipolar disorders. These measures were included because they address good clinical practice associated with positive outcomes. For example, rapid follow-up after an emergency room visit is associated with improved patient functioning and lower costs. Measures that address access and availability of care include access to preventive and ambulatory care, access to primary care physicians, and use of first-line for children on antipsychotics. These measures are included for their overall preventive value and association with decreased use of emergency services. The mental health utilization reports on services ranging from inpatient through outpatient and includes telehealth. These measures can be monitored by race and ethnicity to keep a focus on reducing health disparities. The data should also be categorized to tease out the distinct populations of interest to include early childhood, elementary aged children, adolescents and transition-aged young adults. Concerning the benchmarks, given there is little guidance to be had from other sources, the recommendation is that a process be used similar to that which is already in use for the Sarasota scorecard. Local benchmarks can be established over time and adjusted based on changing local priorities.

Objective 7: Strategic Framework for Change

This section of the report includes a set of policy recommendations that are based on the findings of the environmental scan. The policy recommendations align with the System of Care approach that provides an organizing framework for systemic change supported by core values and principles. The System of Care definition being used is:

> A broad framework of effective services and supports for a defined multi-system involved population, which is organized into a coordinated network, integrates care planning and care management across multiple levels, is culturally and linguistically competent, builds meaningful partnerships with families and with youth at service delivery, management, and policy levels, has supportive management and policy infrastructure, and is data-driven (Pires, 2010)

Key decision makers in Sarasota County should review, modify, and implement these recommendations as strategic reform moves forward in Sarasota County.

Governing Structure

The priority recommendation is to develop or identify an interagency governing structure and planning process to design and implement a unified and comprehensive health care system in Sarasota. While recommended approaches are discussed, this group will be charged with adding specific objectives, timelines, responsible parties and funding, as appropriate. This system will use evidence-based and promising practices for all of Sarasota's at-risk children and youth and their families including the implementation of standardized and comprehensive trauma-informed screening and assessment tools, a comprehensive array of services and supports, clear entry points to the system, and intensive care coordination.

A sub-committee of the Community Alliance, the Behavioral Health Stakeholders Consortium, was formed as a result of the SCOPE Mental Health Report's recommendation in 2003 and charged with overseeing coordination of mental health services, to provide guidance to the Managing Entity and to monitor patient experience, outcomes, and satisfaction within Sarasota's behavioral health system. This group currently has members from family and consumer advocacy groups, but this representation should be expanded to include greater numbers to ensure meaningful family and consumer voice.

Other communities that have implemented similar systems often use a phased-in approach beginning with one or two geographic areas (e.g., North Port or Venice) so that unanticipated problems can be addressed and resolved before moving to other locations. A phased-in approach also offers the opportunity to develop peer-learning opportunities for parents, youth, and providers. Key questions to address in developing the governing structure are:

- Where does the governing structure get its authority to govern?
- Are its members representative of the stakeholders who have an interest in the system of care, including families and youth, primary care practices, health care systems, and behavioral health providers?
- Does the structure have the capacity to govern including needed fiscal resources for functions such as strategic planning and quality assurance?

System Entry Points

One of the System of Care functions that requires structure is system entry/access. Both key stakeholders and parents discussed how challenging it is for parents and caregivers to seek and find help in Sarasota County. Different communities resolve the problem of creating organized pathways to services in different ways. Some communities designate a single point of access for system entry; most of the feedback for this study pointed towards a single point of access. This

single point of access typically assumes countywide responsibility for community education and information, screening and assessment, and referrals. Other communities develop multiple points of access, based on either geography and/or child-serving systems such as child welfare and juvenile justice. Some communities have placed parent or consumer navigators at these entry points. The role of these navigators is to help parents and consumers get to referral sources, and to introduce parents and consumers to informal sources of support such as parent support groups. The entity responsible for governance and strategic planning needs to decide what access structure works best for Sarasota.

In 2017, Sarasota County underwent a Sequential Intercept Mapping process (CJMHTA, 2017) to map the criminal justice system to identify points of 'interception' to divert or intervene for individuals with behavioral health disorders, identify the gaps, resources and opportunities within law enforcement and the existing service systems and to develop a strategic plan to guide criminal justice diversion and treatment. Although focused on adults only, one of the priority areas was to establish a centralized triage system. The current implementation should be continued but expanded to include justice- involved children and youth as well.

Standardized Comprehensive Trauma-Informed Screening and Assessment Protocols

The planning process should include the selection of these screening and assessment tools. These protocols will ensure that all children, adolescents and young adults receive appropriate services and levels of care. In addition to the designated system entry points, primary care practices, federally qualified health centers, and early education providers should implement these protocols. We know from other states and communities that have implemented these procedures that a necessary component is ensuring that all screening and assessment points know the appropriate referral resources and mechanisms.

Data from the Trauma-Informed Care survey of Sarasota's behavioral health community and from the stakeholder interviews suggests that there is a growing awareness of the need for trauma-informed care, trauma specific services and the tools necessary to identify trauma exposure. The survey findings indicate that this awareness is still largely focused on trauma and its effects on the individual. Training in this regard for both behavioral and primary care providers should continue. In addition, to become a trauma–informed community, there needs to be an organizational and system level assessment of practices that contribute to or mitigate trauma in service systems to guide selection of trauma-informed practices and their implementation. There is currently a circuit-wide workgroup on trauma–informed care chaired by the Department of Children and Families' Community Development Administrator that should receive continued support. The third recommendation would be to implement universal adverse childhood events (ACE) screenings in primary and behavioral health settings.

Another recommended approach to help mitigate the effects of trauma of children who have experienced neglect and abuse stemming from child protective investigations and removals is the Handle With Care initiative implemented in Manatee County. This initiative alerts school personnel about children who have witnessed visits from child protective investigators and may have been removed from their homes due to child abuse and neglect overnight so that they may be treated using trauma-informed approaches when they return to school.

Financing Strategies and Structures

Our findings indicate that insurance coverage limitations (both Medicaid and commercial insurance) drives the choices that parents (and providers) make about what services are available and where they are located. The first rule about financing in systems of care is that system design should drive financing rather than financing dictating service choices. Communities across the country have implemented a variety of financing strategies including redeployment of existing dollars, creating new revenue sources such as the Children's Services Councils in Florida,

maximizing federal revenue sources, and creating new structures such as pooled, blended, and braided funding. These new structures often include agreements with other child serving systems such as child welfare, schools, and juvenile justice that make available general revenue funds from these systems.

There are good examples to guide revenue maximization and systematic examination of funding streams. Orange County, Florida conducted such an analysis in 2013 in support of its system of care using Armstrong, et. al's (2006) methodology. Another strategy currently in use was developed and is being piloted for child welfare but the methodology could be extended to all children with behavioral health issues. The Child Welfare Behavioral Health Regional Financial Planning Tool (Department of Children and Families, 2018) was developed in partnership with the Casey Family Programs and the Department of Children and Families. This tool is intended to guide a collaborative cross-system financial planning process that supports an array of evidence–based practices and maximizes funding streams, including those available through the Managing Entities, Medicaid, Community-Based Care agencies, and local funders. This tool is currently being piloted in Sarasota County under the auspices of the Behavioral Health Stakeholders Committee.

Quality Assurance Mechanisms

One decision that the governing structure needs to make is what entity will be responsible for quality assurance and data integrity. The governing structure in a System of Care needs ready access to reliable data about how the system is functioning at the system and the child and family level. Data that need to be available include demographics of youth served, lengths of stay, whether referral linkages are effective, service gaps, quality of care, and youth and family outcomes. One area where putting into place a set of quality assurance mechanisms may be useful is the use of psychotropic medications. Consideration should be given to quality indicators at several junctions: the appropriateness of the initial decision to prescribe a psychotropic medication, including whether other evidence-based practices have been implemented; a follow-up assessment in three months to decide whether the medication is effective and evaluate any side-effects; and periodic assessment regarding the use of medications rather than other types of interventions.

Creating an infrastructure for sharing data is a necessary element to any quality assurance and to efficient care coordination. There are several models in Florida for confidential data sharing and exchange that contributes to care coordination at the individual child, family or consumer level and which also supports data informed decisions and management at the agency and system level. Broward County's Integrated Data System (Gallagher & Nelson, 2017) and Manatee County's implementation of a health information exchange (Barnett personal communication, 2019). The Agency for Healthcare Administration and the Department of Children and Families also have or are piloting HIEs to improve service coordination and system efficiencies.

Intensive Care Coordination

Our findings indicate a lack of care coordination for high-need youth in Sarasota County who interact with several providers and/or child-serving systems, such as juvenile justice, special education, and child welfare. One function of a system of care is intensive care coordination for these youth. An intensive care coordinator works with a small number of families (e.g. on a 1-8 or 1-10 ratio) with children with multiple and complex needs. The care coordinator has access to an array of providers and informal supports and often has access to flexible resources for the individualized needs of families. Wraparound is one approach that many communities use for intensive care coordination. In Florida, there is a statewide system of care initiative that is actively working with Medicaid managed care plans to make wraparound a billable service.

To build on work in the Sarasota community, the Master Case Management model used in the Homeless Response System might be considered as a model for connecting existing case management and care coordination programs including wraparound, Community Action Teams and targeted case management services and connect case management to the centralized receiving system as it is fully implemented.

Family Supports

Our findings indicate that there are limited options for parents in Sarasota County who are seeking help from the time of service initiation (Where do I go for help?) and through the stages of treatment planning and care implementation. We know that other parents and caregivers with a child or adolescent with mental health challenges are the greatest sources of informal support for parents. Many communities have created structures of family support including family support groups that are readily accessible and well-advertised, family navigators at system entry points, family warm lines that offer telephone and text support by other caregivers, and family organizations. The strategic planning process will need to decide what structures will be most effective and financing mechanisms.

Prevention and Early Intervention Services

States and communities struggle with how to finance prevention and early intervention services. Due to limited resources, one starting point could be early childhood. The Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT) is federally mandated for screening Medicaid-eligible children ages 0 to 21, and linking them to appropriate physical and mental health services. EPSDT is the broadest Medicaid entitlement to services for children and youth and requires periodic screens beginning at birth and the provision of medically necessary services, even if those services are not included in a state's Medicaid plan. In addition, the federal Department of Education through Title 1—Improving the Academic Achievement of Disadvantaged Individuals with Disability Education Act (IDEA) offers Part C services to infants and toddlers. State health departments are typically responsible for Part C implementation. Some states and communities are linking with PART C providers and asking them to incorporate mental health screening tools into their assessment protocols. Other communities are partnering in a similar way with Head Start and Early Head Start programs as a strategy for early identification.

Training and Professional Development

In addition to Trauma – Informed Care Training noted above, there is a continued need to expand the capacity of Sarasota service providers, educators and justice system staff. As noted in the 2017 SIM report (CJMHTA, 2017), there is a continued need to provide Crisis Intervention Training to law enforcement and this need is heightened in the wake of the Parkland massacre and expansion of the role of school resource officers.

Respondents often noted the need for attracting additional behavioral health professionals to the community, notably but not limited to child psychiatrists. There is a noted shortage of child psychiatrists nationwide (National Council Medical Director Institute, 2017) and a need for a multi-pronged approach. One part of the solution is to expand access to telepsychiatry and telemedicine and ensure adequacy of reimbursement for these services. Attracting other professionals, such as Advanced Registered Nurse Practitioners (ARNPs) and Physician's Assistants with psychiatric specializations. This will involve state and federal level policy advocacy to ensure adequacy of reimbursement. Other community investments might be establishing a fund for student loan forgiveness program in exchange for a specified years of service in the Sarasota Community.

Supporting schools and enhancing their response to students with behavioral health challenges needs to be an ongoing focus. There are now mental health professionals in all of the County's

high schools and a plan for the sustainability of these resources is needed. Another community resource available to school resource officers and guidance staff is the Mobile Crisis Team. Attention is needed to ensure the protocols between these entities are working smoothly and are getting students needed support as quickly as possible.

Other Community Supports

As noted, there are strengths in Sarasota's behavioral health system that should continue to be supported to promote maximal coordination and attention to vulnerable populations including the committees focused on "lock–outs", and the Youth and Families At-Risk staffing committee. Committees or task forces will need to be added under the Behavioral Health Stakeholders Committee to address the recommendations in this report, identify additional and more specific strategies within each recommendation area, and to map out the implementation timelines, funding, and responsible parties.

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Appendix A: Data Elements Available through CHARTS

Available at http://www.flhealthcharts.com/charts/Default.aspx

Child indicators

Children ages 1-5 receiving mental health treatment services

Hospitalizations for mental disorders (schizophrenic disorders, mood and depressive, mental health disorders excluding drug and alcohol)

Hospitalizations for self-inflicted injuries

Hospitalizations for eating disorders

Estimated number of youth with emotional and behavioral disorders (population estimates based on DHHS report of mental health 1996)

Children in schools K-12 with emotional and behavioral disabilities (from Florida DOE)

Percent of students who feel safe at school (middle and high school) - Florida Youth Tobacco Survey

Adult indicators

Adults who always or usually receive the social and emotional support they need

Adults who had poor mental health on 14 or more of the last 30 days

Adults told they had a depressive disorder

Adults whose poor physical or mental health kept them from doing usual activities on 14 or more days,

Adults with good mental health

Average days where poor mental or physical health interfered with activities of daily living (Among adults who report poor physical or mental health)

Professional / capacity

Licensed mental health professionals per 100,000

Appendix B: Summary of Open Feedback from Stakeholder Survey

When asked to identify **barriers to accessing mental health services** in Sarasota County, the following barriers were stated:

- Not enough community services available
- Lack of awareness of available resources
- Lack of transportation to make it to appointments
- Local services are not suited to treat children with complex mental health issues
- Lack of children-focused specialists (i.e. child psychologists, child psychiatrists)
- Difficult to receive adult services after youth are no longer eligible to receive child services
- Lack of providers accepting certain insurances or patients with no insurance
- Parents not following through with treatment of child
- Location and hours of services provided
- Not enough providers in the area
- Stigma associated with mental health issues in children
- Shortage of bilingual clinicians

When asked to describe the **characteristics of the population of concern** in Sarasota County, the following characteristics were stated:

- 0-18-year-old children who have been Baker Acted on multiple occasions
- Mostly children who speak English and or Spanish
- Minority individuals (e.g. Black and Hispanic)
- Young people who experience challenges adapting and/or succeeding in their environment
- Pregnant women
- Children whose families are living in poverty
- Children whose parents are or have been incarcerated
- Children with early diagnoses of mental health disorders
- Children in the state child welfare system
- Children and adolescents exposed to traumatic childhood evens that exhibit behavioral concerns and mood disturbances
- Low income, -uninsured, -minority groups
- Children with involvement in the DJJ/court system
- Children with limited to no family support

When asked to note any **agencies or stakeholders that should be involved in cross-sector collaborations**, the following agencies were listed:

- Centerstone
- Law enforcement
- SPARCC
- Day care
- Healthy Start
- Bay Area Youth Services
- Teen Court
- Coastal Behavioral Care
- Primary care
- School district
- Families of children involved
- Managed care entities
- Advocacy groups
- Service providers
- RADical Healing Inc.
- Specific disability organizations

When asked to note any other **impacts of untreated mental illness** that they have noticed in their area, the following impacts were stated:

- A lot of young adults who do not complete their education
- Young adults are often left unemployed
- Limited options for jobs that provide a livable wage
- Development of trauma related issues

Unaddressed challenges, needs, and barriers to providing mental health care to children, youth, and young adults ages 0-24 in Sarasota County:

- Need more prevention services that begin in preschool and continue throughout every grade level
- Fetal alcohol syndrome
- Limited providers for serious mental illnesses
- Lack of funding for mental health services

Appendix C: Key Mental Health Providers Reported by Stakeholders

Mental Health Providers in Sarasota County
The Academy at Glengary
Bayside Center for Behavioral Health
Big Bear Behavioral Health
Centerstone
Center for Change of Florida
Circle of Friends Preschool
Clinic in Northport
Coastal Behavioral Healthcare
Community Action Teams (CAT Teams)
Early Learning Coalition
Family Life Intervention Program
First Step of Sarasota Inc.
Florida Center for Early Childhood
Forty Carrots Family Center
Girls Inc. of Sarasota County
The Glasser/Schoenbaum Human Services Center
Harvest House
Healing Transitions Creative Counseling for Children & Families Inc.
Healthy Start
Jewish Family and Children Services
Journeys
Religious Affiliations
Sarasota Memorial hospital

Appendix D: Health plan/Employer Data Information System (HEDIS) Measures

Effectiveness of care measures

Behavioral Health

- Antidepressant Medication Management
- Follow-Up Care for Children Prescribed ADHD Medication
- Follow-Up After Hospitalization for Mental Illness
- Follow-Up After Emergency Department Visit for Mental Illness
- Follow-Up After Emergency Department Visit for Alcohol and Other Drug Abuse or Dependence
- Diabetes and Cardiovascular Disease Screening and Monitoring for People With Schizophrenia or Bipolar Disorder
- Adherence to Antipsychotic Medications for Individuals With Schizophrenia
- Metabolic Monitoring for Children and Adolescents on Antipsychotics

Access and availability

- Adults' Access to Preventive/Ambulatory Health Services
- Children and Adolescents' Access to Primary Care Practitioners
- Use of First-Line Psychosocial Care for Children and Adolescents on Antipsychotics

Utilization

Mental Health Utilization

- Inpatient.
- Intensive outpatient or partial hospitalization.
- Outpatient.
- Emergency department (ED).
- Telehealth.
- Any service.

Source: https://www.ncqa.org/hedis/measures/


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