



**ANNUAL REPORT**  
**FISCAL YEAR 2019**  
(July 1, 2018- June 30, 2019)



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**CRSA CHANGES LIVES EVERY DAY  
BY HELPING YOUTH FIND PATHWAYS  
TO HEALTHY FUTURES**

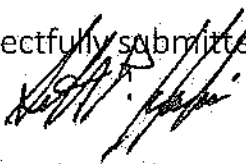
LETTER OF TRANSMITTAL

Governor Bruce Rauner  
Members of the General Assembly  
State Agency Directors and  
State Superintendent of Education  
Springfield, Illinois

Dear Governor Rauner, Members of the General Assembly, State Agency  
Directors and Superintendent of Education:

On behalf of the membership of the Community and Residential Services Authority,  
I transmit herewith the 32nd Annual Report. I am pleased to present this summary  
of activities for Fiscal Year 2019 in accordance with the requirements as set forth  
in Ch. 122, Sec. 14-15.01 of the Illinois School Code.

Respectfully submitted,



Seth Harkins, PhD  
Chairperson

### LEGISLATIVE MEMBERS

Senator Jennifer Bertino-Tarrant  
Senate Committee on Elementary &  
Secondary Education  
Ms. Carie Johnstone, Designee

Senator Chuck Weaver  
Senate Committee on Elementary &  
Secondary Education  
Mr. Matt George, Designee

Representative Fred Crespo  
House Committee on Elementary &  
Secondary Education  
Dr. Seth Harkins, Designee, Chairperson\*

Representative Robert Prichard  
House Committee on Elementary &  
Secondary Education  
Dr. Kathleen Briseno, Designee\*

### STATE AGENCY DESIGNEES

Ms. Monica Wright  
Illinois Department of Healthcare  
and Family Services

Ms. Juliana Harms\*\*  
Illinois Department of Children and Family  
Services

Mr. Randy Staton\*  
Illinois Department of Human Services  
Division of Rehabilitation Services

Ms. Maureen Haugh-Stover  
Illinois Department of Human Services  
Division of Developmental Disabilities

Mr. Mark Smith\*  
Illinois Department of Juvenile Justice

Ms. Lisa Betz  
Illinois Department of Human Services  
Division of Mental Health

Ms. Brittany Rosenbloom  
Illinois Attorney General's Office

Ms. Abbey Storey  
Illinois State Board of Education

Ms. Julie Stremmlau, Secretary\*  
Illinois Department of Human Services  
Office of Family and Community Services

### GOVERNOR'S APPOINTEES

Mr. Neal Takiff  
Gubernatorial Appointee

Dr. Robert Bloom\*  
Gubernatorial Appointee

Mr. Gary Seelbach\*  
Gubernatorial Appointee

Dr. Andrew Beatty  
Gubernatorial Appointee

Judge Stephen Sawyer  
Gubernatorial Appointee

Mr. Merlin Lehman\*\*  
Gubernatorial Appointee

\* Executive Committee

\*\*Executive Committee Alternate

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## About the CRSA

The Community and Residential Services Authority (CRSA) is an interagency group created by the State Legislature in 1985. The CRSA is responsible for identifying and addressing barriers facing parents, professionals and providers when trying to get needed services and programs for youths with a behavior disorder or a severe emotional disturbance and their family. We work directly with parents and families of the most at-risk children in Illinois. CRSA serves the entire state of Illinois. It is not an overstatement to say that the children that the CRSA become involved with are impacted by significant challenges, engage in severe behaviors, and often have the most difficulty in accessing the current existing supports and services available to Illinois youth.

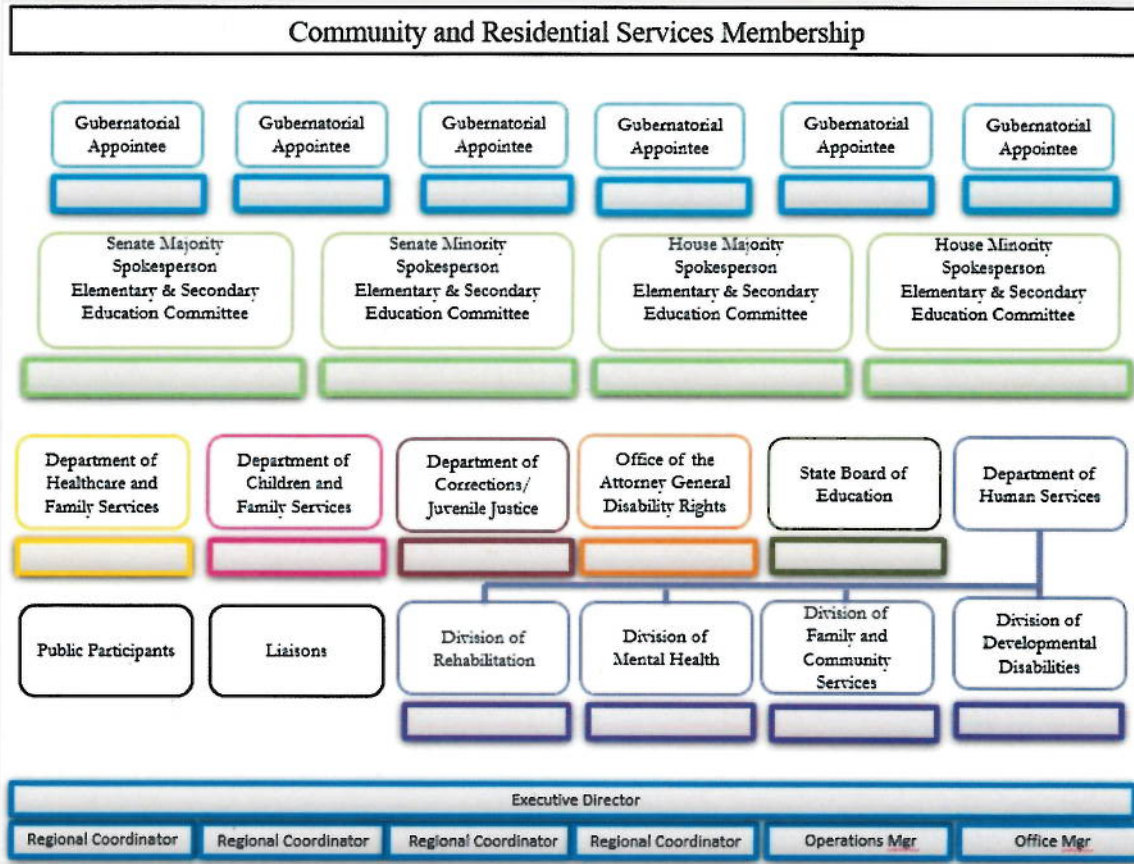
Children who exhibit multiple impairments/disabilities, including behavior disorders or severe emotional disturbances, historically present challenges to Illinois' state service system as agencies and schools try to address the diverse service needs of this population. Many of these children do not clearly fit the eligibility criteria or funding streams of state and local public agencies and therefore, go un-served or are underserved by the very systems established to help them.

**OUR CRSA MISSION** is to promote a network of resources for Illinois youth with social and emotional health conditions to receive timely and appropriate access to the services they deserve.

**OUR CRSA VISION** is that every youth in Illinois shall be socially and emotionally healthy enough to have the opportunity to achieve their fullest potential and participate in developing their identity and role in society.

The **CRSA Board** consists of representatives of the youth serving state agencies, members of the legislature and persons appointed by the Governor. The board meets regularly to address systems gaps and persistent barriers to accessing services for youth with emotional disabilities.

The CRSA has nineteen members: nine representatives of child-serving state agencies, six public and private sector gubernatorial appointees and four members of the General Assembly or their designees. The CRSA employs an Executive Director who operates with the assistance of three expert Regional Coordinators and two support professionals to fulfill the CRSA's statutory mandates.



CRSA BOARD MEMBERS

- Representatives of the House and Senate Elementary and Secondary Education Committees (4)
- Governor's Appointees (6)
- Attorney General's Office (Disabled Persons Advocacy Division)
- Department of Children and Family Services
- Department of Healthcare and Family Services
- Illinois State Board of Education
- Department of Juvenile Justice
- Department of Human Services
- Division of Mental Health
- Division of Developmental Disabilities
- Division of Rehabilitation Services
- Division of Family and Community Services

The CRSA Staff work for the initiatives set by the CRSA board and established legislative objectives. We Listen and are quick to respond to calls for help for youth who have emotional difficulties and behavioral disabilities. We are personally accessible to assist in coordinating a plan of care.

We Collaborate to ensure that services are planned in collaboration with all appropriate child-serving systems in the youth's natural environment when possible.

**We are Competent** to promote family-focused/child centered – services that are developmentally appropriate, strength based, child specific and meet the individual needs of the youth and family.

**We are Respectful** regarding the behavior, ideas, attitudes, values, beliefs, customs, languages, rituals, and practices characteristic to the family's cultural group.

**We have Integrity** and protect participant confidentiality. We deal honestly with the public, our participants and with one another.

**We are Reliable** to assist in the reduction of barriers to mental health and educational services for CRSA participants.

**We are Successful** in working with our partner agencies and communities to find solutions to complex barriers that otherwise could prevent youth with social and emotional disabilities from getting the services they need.

**We Develop** policy statements when needed for interagency cooperation and comment on relevant legislation affecting services to all individuals under 22 years of age with a behavior disorder.

**We Report** annually to the legislature and to the Governor.

**We Resolves Disputes** when there is a disagreement between a parent and an agency or between two or more agencies regarding a plan of services that cannot be implemented through CRSA staff assistance, CRSA Board members can convene to resolve such disputes

The State of Illinois provides an extensive array of services to its children and adolescents, but like many other states, has encountered difficulty connecting various public and private services. Children and adolescents who are labeled severely emotionally disordered or behaviorally disordered have multiple service needs. They frequently require a blend of educational, social, psychological and other support services that may not clearly fit the service eligibility criteria or funding patterns of public agencies. These circumstances may create confusion and occasional disputes between state and local human service agencies and schools and between agencies and parents. The CRSA assists all parties in obtaining the overall objective regarding the best interest of the child on our caseload. When that cannot happen in a collaborative agreement at the Regional Coordinator level, the CRSA board can review the case in a Dispute Resolution meeting. (Dispute Resolution described later in this document on page 4)

The Community and Residential Services Authority (CRSA) has been able to identify the Illinois social service barriers for children with complex mental health challenges. In FY19 the CRSA facilitated cohesive complex service planning for 347 children with severe behavioral/emotional disabilities and or complex educational needs who faced barriers to accessing the Illinois public and private services designated to help them.



## POWERS AND DUTIES

<sup>1</sup>CRSA was given the following powers and duties in legislation:

- To conduct surveys to determine the extent of need, the degree to which documented need is currently being met and feasible alternatives for matching need with resources.
- To develop policy statements for interagency cooperation to cover all aspects of service delivery, including laws, regulations and procedures, and clear guidelines for determining responsibility at all times.
- To recommend policy statements and provide information regarding effective programs for delivery of services to all individuals with a behavior disorder or a severe emotional disturbance in public or private situations.
- To review the criteria for service eligibility, provision and availability established by the governmental agencies represented on this Authority, and to recommend changes, additions or deletions to such criteria.
- To develop and submit to the Governor, the General Assembly, the Directors of the agencies represented on the Authority and the State Board of Education a master plan for individuals with a behavior disorder or a severe emotional disturbance, including detailed plans of service ranging from the least to the most restrictive options; and to assist local communities, upon request, in developing or strengthening collaborative interagency networks.
- To develop a process for making determinations in situations where there is a dispute relative to a plan of service for individuals or funding for a plan of service.
- To provide technical assistance to parents, service consumers, providers, and member agency personnel regarding statutory responsibilities of human service and educational agencies, and to provide such assistance as deemed necessary to appropriately access needed services.

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<sup>1</sup> (105 ILCS 5/14-15.01) (from Ch. 122, par. 14-15.01)  
Sec. 14-15.01. Community and Residential Services Authority

## OPERATIONS

The following is a description of the operational structure of CRSA when receiving a referral:

### Intake

- Intake involves receiving, establishing eligibility for CRSA services, documenting and processing the issues, complaints or questions from an individual, or from an individual on behalf of an organization.
- Personnel implementing Intake: CRSA has a designated Intake Coordinator.

### Implementation

- Implementation involves general information gathering, making referrals, specialized resource acquisition, coordination with public and private organizations regarding a common plan of care.
- Personnel: CRSA employs three Regional Coordinators statewide to implement these objectives.

### Dispute Resolution

- Dispute resolution occurs when there is a disagreement between a parent/guardian and an agency represented on the Authority regarding a plan of services; or a disagreement between two or more member agencies regarding implementation of a plan of services. The Authority has a mandate "to develop a process for making determinations in situations where there is a dispute relative to a plan of service for individuals or funding for a plan of service". While each state agency has its own internal review processes, Illinois needed a statewide process to resolve multiple-agency disputes so it was built into the CRSA legislation.
- Personnel: The director and board chair determines the dispute resolution team, which consists of relevant board members.
- Process: staff and members collaborate to explore voluntary solutions to complex multi-agency, multi-systems issues regarding a plan of care. During FY19, all potential dispute resolution cases were resolved through informal consults with relevant agency board members.

**The CRSA Regional Coordinator:** CRSA is a unique agency, which will never have the same exact issue for any given case. CRSA Regional Coordinators are consultants, troubleshooters and sometimes a "systems alarm bell". Overall, Regional Coordinators mostly function as a "systems-guide" and collaborative partner for parents, agencies and communities. CRSA staff understand protocols for accessing established state services and resources for youth with behavioral health care needs.

**DEMOGRAPHICS OF YOUTH REFERRED TO CRSA:** During FY19, CRSA cases are complex, requiring sustained technical assistance, often over a period of months in order to access needed services. The CRSA has a case monitoring system that tracks key client demographics, reasons for referrals and diagnostic information. From these data, fiscal year trends were obtained.

**FISCAL YEAR 2019 EXPENDITURES**  
**COMMUNITY AND RESIDENTIAL SERVICES AUTHORITY**  
**FY 2019**  
**APPROPRIATION/EXPENDITURE SUMMARY**

<b>FY 2019 APPROPRIATION</b>	<b>\$569,000.00</b>
<b>FY 2019 EXPENDITURE</b>	<b>\$546,518.01</b>
<b>LAPSED FUNDS</b>	<b>\$22,481.99</b>

TYPE OF EXPENDITURE	ALLOTMENT	EXPENDITURE	BALANCE
<b>PERSONNEL SERVICES</b>			
CRSA Employee Salaries	\$410,000.00	\$403,440.00	\$6,560.00
Retirement Reserve	\$25,000.00	\$0.00	\$25,000.00
Benefits Package	\$30,400.00	\$29,213.50	\$1,186.50
Contractual Employee	\$20,000.00	\$5,021.00	\$14,979.00
<b>TRAVEL</b>			
Staff Travel	\$30,000.00	\$26,894.56	\$3,105.44
Members Travel	\$10,000.00	\$2,558.69	\$7,441.31
<b>PROFESSIONAL DEVELOPMENT</b>			
Staff Development	\$2,000.00	\$1,676.00	\$324.00
Member Development	\$2,000.00	\$0.00	\$2,000.00
<b>OPERATING EXPENSES</b>			
CDW Governmental	\$0.00	\$40,173.40	(\$40,173.40)
Equipment & Office Supplies	\$10,000.00	\$15,328.84	(\$5,328.84)
Facility Lease	\$28,600.00	\$14,336.70	\$14,263.30
Meeting Expense	\$1,000.00	\$0.00	\$1,000.00
Phone, Postage & Supplies	\$10,000.00	\$7,875.32	\$2,124.68
	<b>\$579,000.00</b>	<b>\$546,518.01</b>	<b>\$32,481.99</b>

\* These are funds which were allocated to meet anticipated needs but which did not need to be expended during this Fiscal Year.

## DEFINITION PAGE



- ❖ Advocates: State, federal and private advocacy agencies/groups/individuals, lawyers
- ❖ CIL: Community for Integrative Living
- ❖ CRSA: Community and Residential Services Authority
- ❖ DCFS: Illinois Department of Children and Family Services
- ❖ DHS: Illinois Department of Human Services
- ❖ DJJ: Illinois Department of Juvenile Justice
- ❖ FFP: Federal Financial Participation
- ❖ FSP: Family Support Program
- ❖ HFS: Illinois Department of Healthcare and Family Services
- ❖ ICG: Individual Care Grant
- ❖ IDD: Intellectual Development Disorder
- ❖ IEP: Individual Education Plan
- ❖ ISBE: Illinois State Board of Education
- ❖ LEAS: Local Educational Agencies
- ❖ NB: NB vs. Norwood class action law suit
- ❖ Parents: Parent(s) or legal guardian
- ❖ SASS: Screening Assessment and Support Services
- ❖ SFSP: Specialized Family Support Program
  
- ❖ Community Agencies:
  - Local community direct service provider agency
  
- ❖ State Agencies:
  - Illinois State Board of Education;
  - Illinois Department of Children and Family Services;
  - Illinois Department of Juvenile Justice;
  - Illinois Department of Healthcare and Family
  - Illinois Department of Human Services:
    - Divisions of Mental Health,
    - Developmental Disabilities,
    - Rehabilitation Services,
    - Family & Community Services

## STATISTICAL SUMMARY

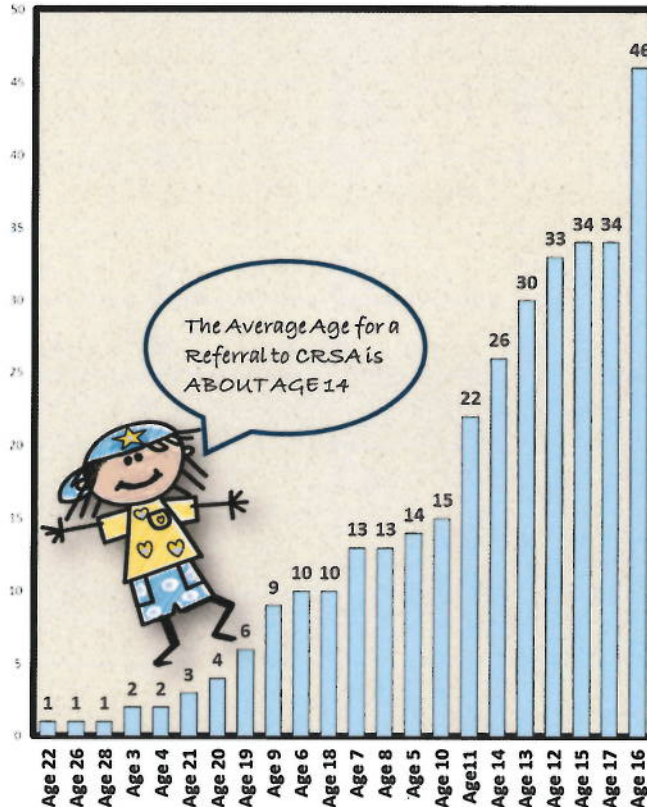
It is common for children and young adults referred to CRSA to have between two to five diagnosed disabilities and to exhibit four or more serious behavior problems at the time of referral. These individuals often had service needs for which two or more member agencies had overlapping service and funding responsibilities.

During FY19, CRSA staff responded to 347 calls for assistance. CRSA records all diagnoses reported by the referral source. Any one child could have more than one condition or diagnosis. The following is a breakdown of the CRSA referred youth's medical coverage, diagnosis, functioning level, and difficulty of care factors as reported to CRSA staff:

CRSA served children from ages three to twenty-eight for the fiscal year 2019. Typically, CRSA only serves youth up to the age they graduate from school however we do receive "information-only" calls on older youth in transition.

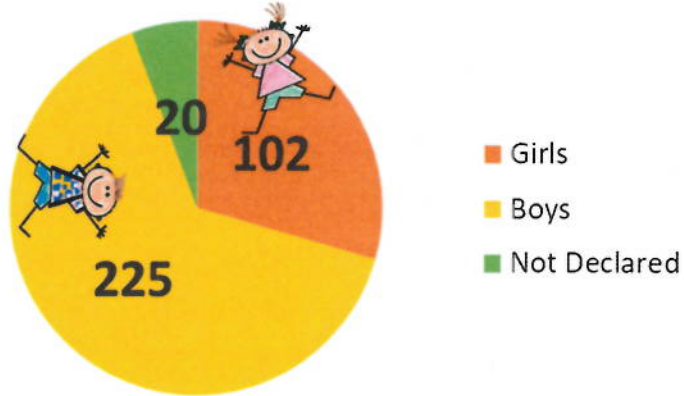
**Age of Youth Referred to CRSA FY 2019**

\* 18 Individuals Did Not Report Age

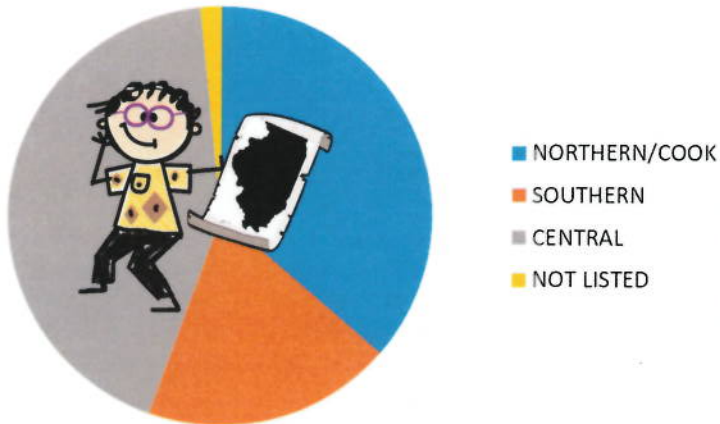


CRSA serves all regions of Illinois. The majority of youth served were in the Central and Northern Regions. We served 225 boys and 102 girls this year. 36% of the CRSA population served were minorities, which is 13% higher than the Illinois per capita minority population. The majority of youth referred to CRSA had Illinois Medicaid as medical coverage.

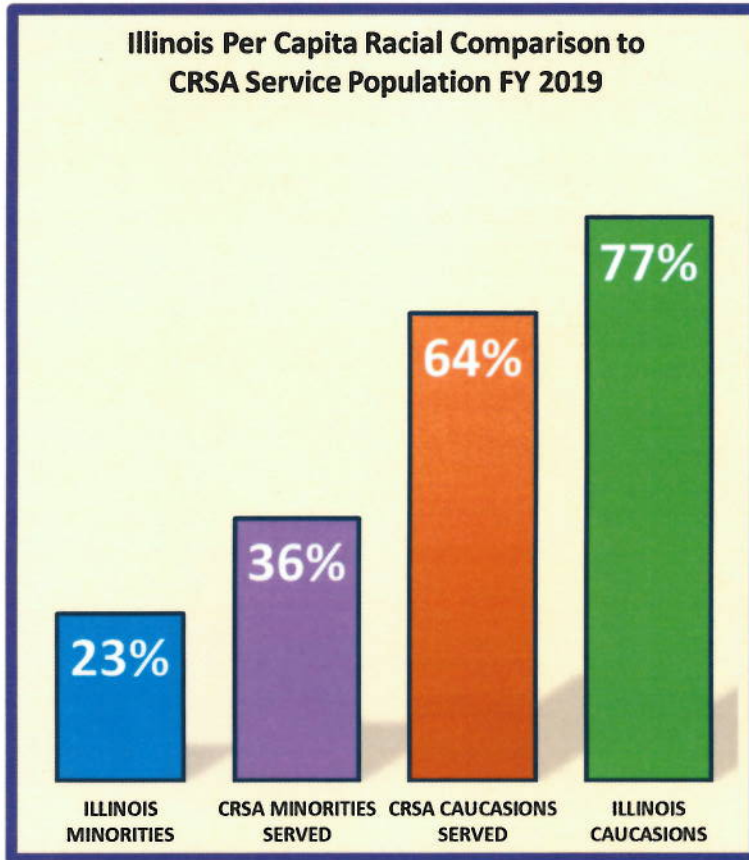
### GENDER OF YOUTH REFERRED TO CRSA FY 2019



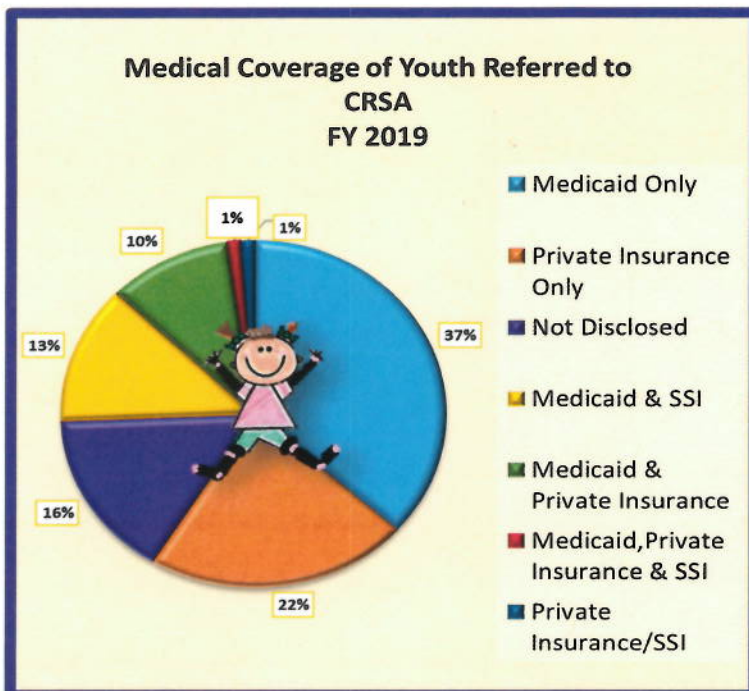
### CRSA REFFERALS BY REGION FY 2019



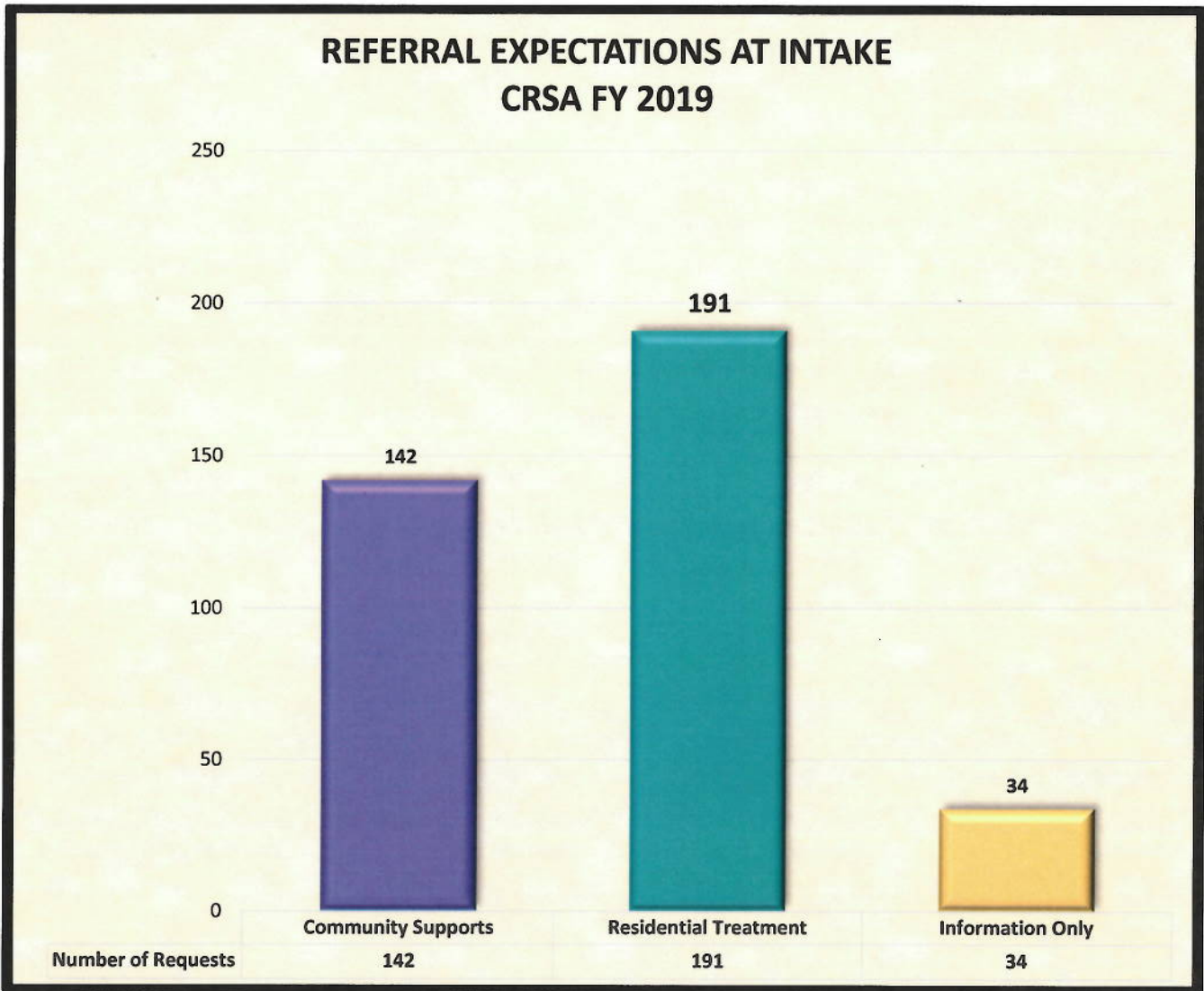




<https://www.census.gov/quickfacts/IL>

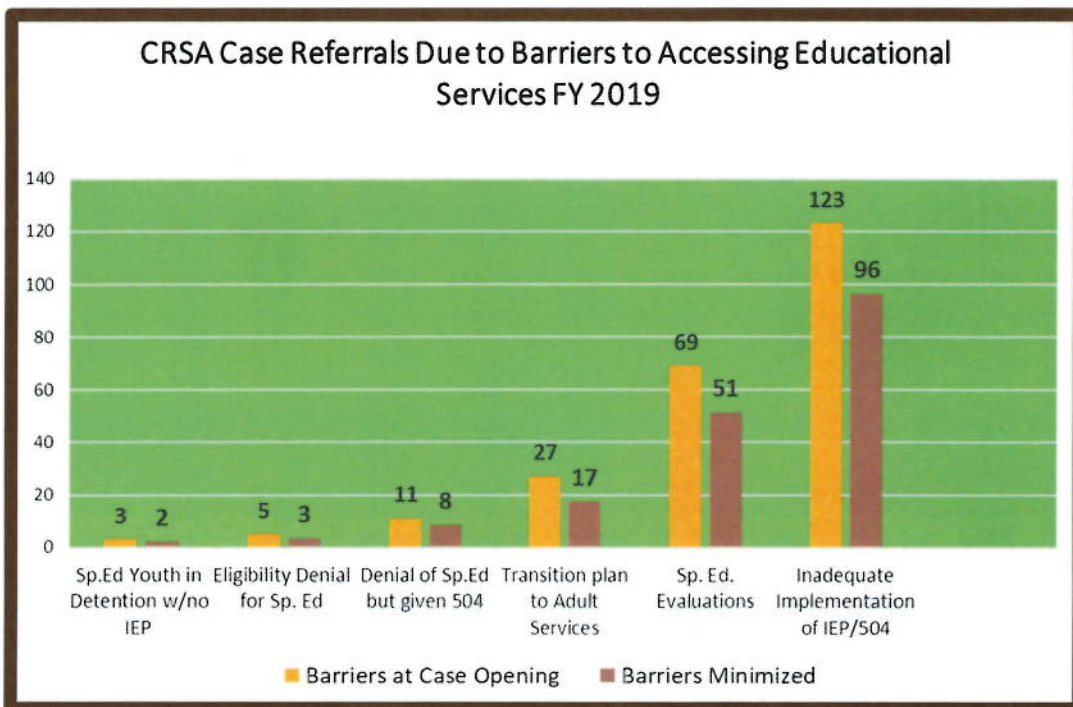
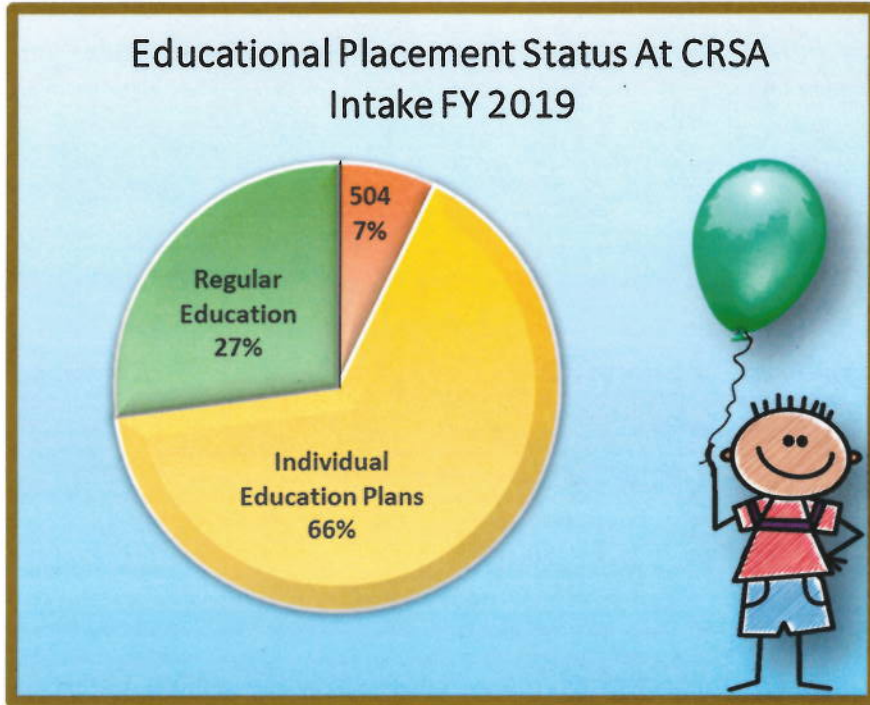


**Services requested at intake:** Because a large portion of the referrals to CRSA from families with children who are demonstrating behavior and emotional difficulties, 52% of our referrals are from families and agencies seeking assistance with obtaining residential treatment for their youth. Most other referrals are regarding assistance with community supports.

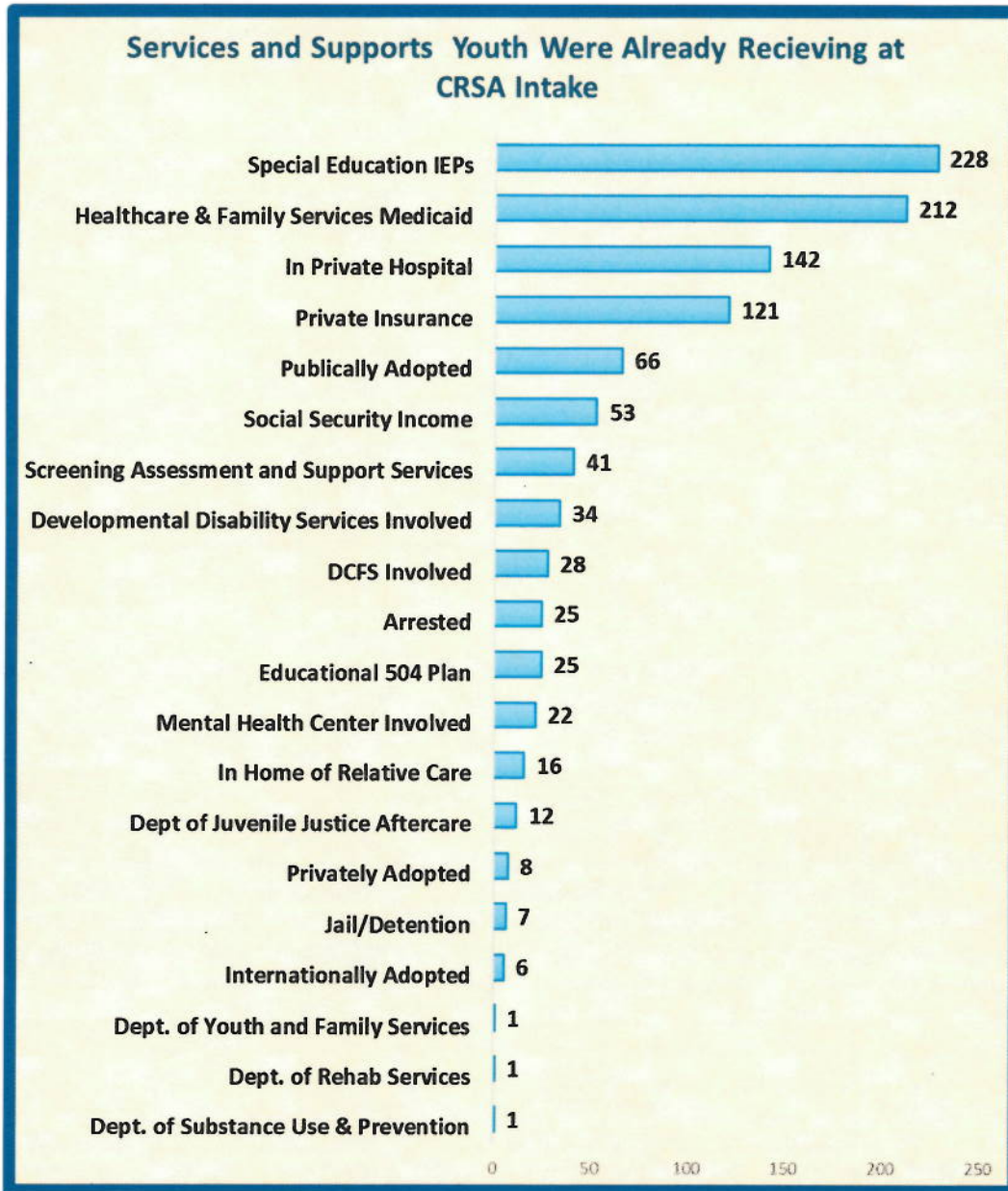




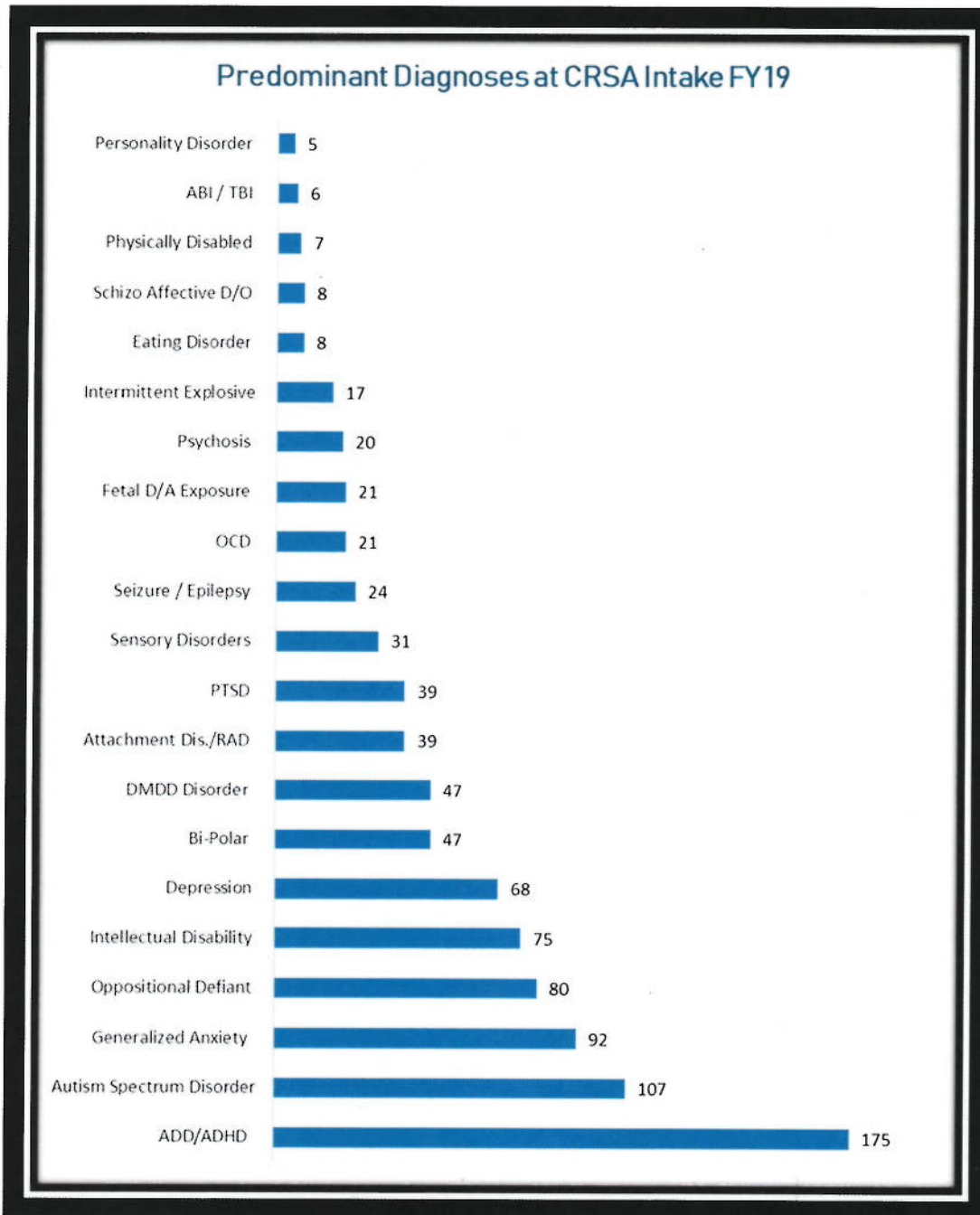
Education services at intake: Other youth referred to CRSA were requesting assistance with educational services. Most youth referred are already receiving special education services. Youth in regular education and ADA 504 plans encompass the other educational status of youth at referral. Sometimes educational barriers to accessing educational services occur. CRSA Regional Coordinators assist the parents in understanding the process to follow in order to obtain an educational plan in the best interest of their child.



Services at intake: CRSA tracks the type of services youth are currently receiving at the time of referral and services that the referents are requesting.

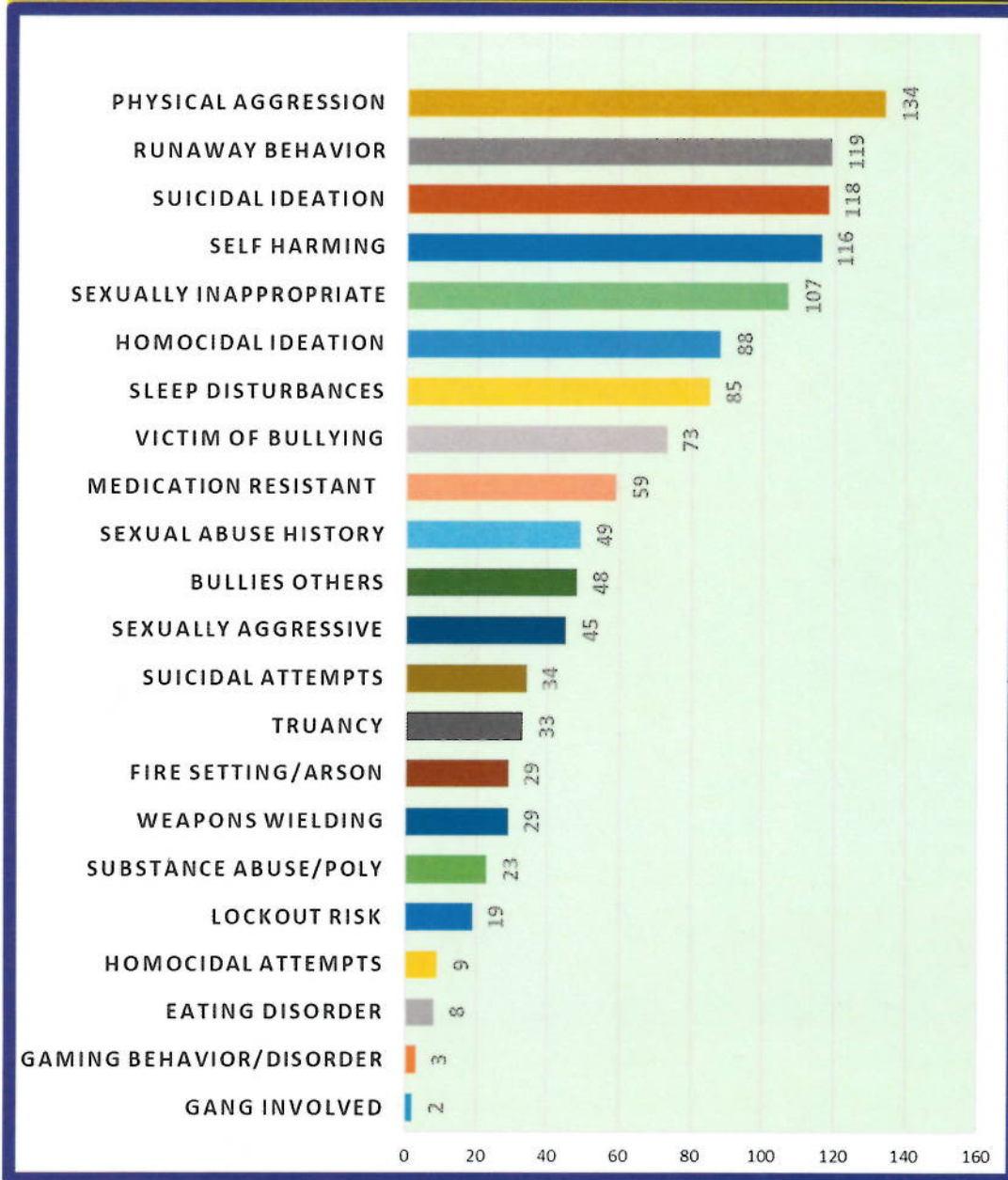


**Diagnosis at intake:** In order to assist in a responsible plan of care, the following chart reflects a youth's predominant diagnoses and difficulty of care factors, when they are referred to CRSA.



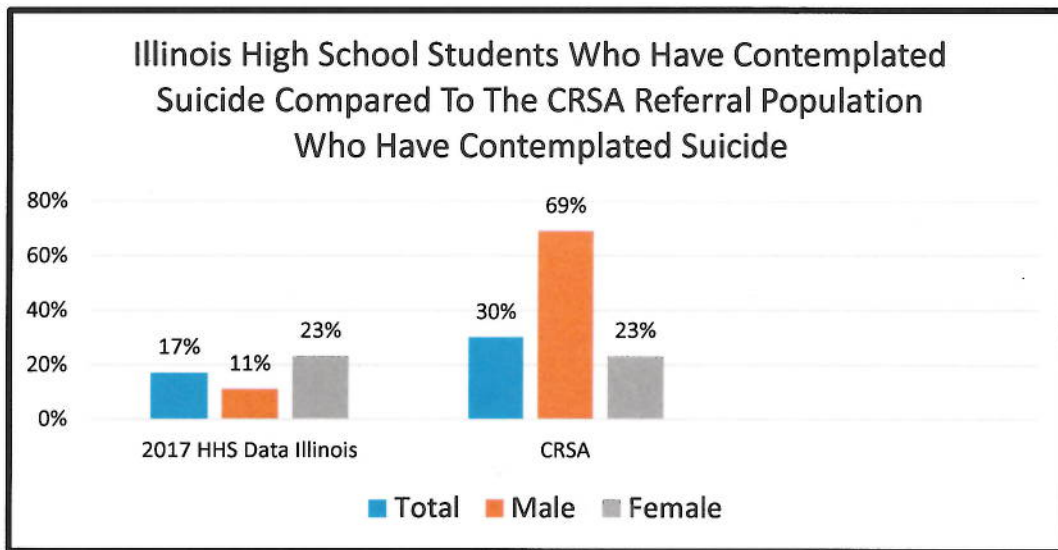


### Difficulty of Care Factors of Youth Referred to CRSA FY 2019

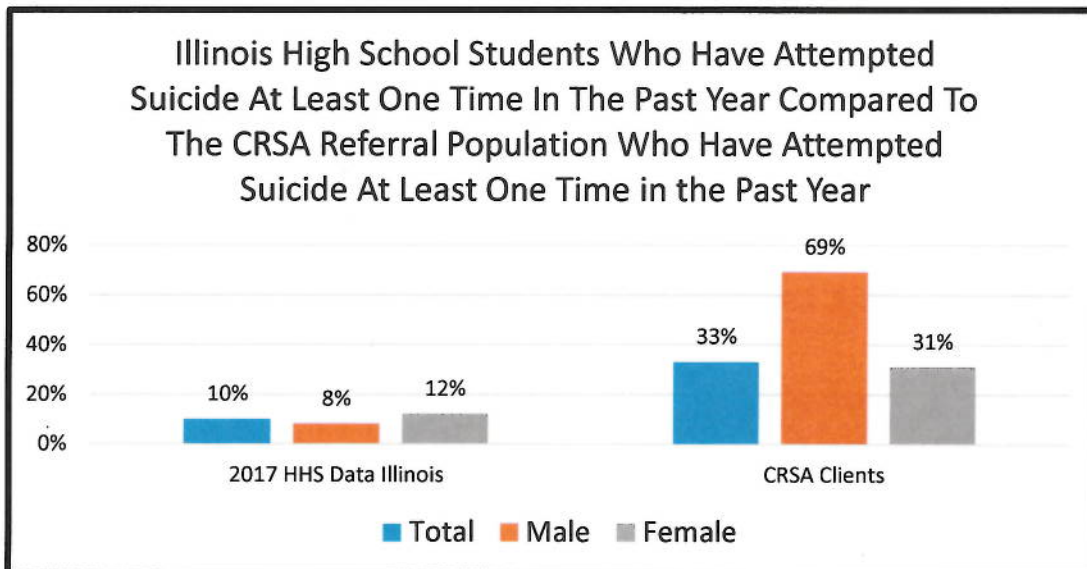


Most Youth Referred to CRSA Have More than One Difficulty of Care Factor.

**Suicidal ideation and attempts tracked at intake:** As noted in FY 2018, suicidal ideation and suicidal attempts amongst high school age youth referred to CRSA continues to be an extraordinarily high compared to Illinois overall statistics for high school age youth. Regarding suicide risks, the following chart is a comparison of CRSA referrals with a survey conducted by U.S. Health and Human Services Illinois Adolescent Health Facts. One can easily see the referrals to CRSA were again, this year, above the Illinois norms for Suicidal thoughts, attempts, and related injuries among high school students (grades 9-12).



<https://www.hhs.gov/ash/oah/facts-and-stats/national-and-state-data-sheets/united-states-adolescent-health-facts/illinois/index.html>



<https://www.hhs.gov/ash/oah/facts-and-stats/national-and-state-data-sheets/united-states-adolescent-health-facts/illinois/index.html>

## FY 2019 OBSERVATIONS FROM CRSA REGIONAL COORDINATORS AND ADMINISTRATION

### TRANSITION:

CRSA Coordinators believe that there is room for improvement in how schools and communities work together to form successful transition plans. Ten percent of the CRSA cases received in FY 19 were for assistance in transitioning to adult services. Presently schools are required to perform a coordinated set of activities to facilitate the child's movement from school to post-school activities called Transition Plans. Adult service linkages that promote independent living or community participation are often difficult for IEP teams to obtain. Currently the Division of Rehabilitative Services has a formal relationship with schools for this purpose but no official relationship between any other HFS or DHS divisions is established statewide. Most other DHS division caseworkers decline invitations to attend IEP's. As a result, graduating youth with IEP's are informed about DHS, and HFS services but are left to their own devices to obtain them.

It would be helpful if HFS and DHS, not just DRS, would collaborate to assist with IEP transition planning. Perhaps in the future, healthcare reform initiatives will allow a new opportunity to align IEP transition services with HFS and DHS to integrate care plans.

Youth in transition from psychiatric residential treatment to home, had difficulty obtaining the stabilizing publically funded home-based transitional support services prescribed at discharge. Of much concern to CRSA staff, were that some of these youths had little to no successful trials of less restrictive levels of care before they were discharged. Once back in their community, some young adults with the primary diagnosis of a mental health disorders requiring a step-down transitional living arrangement, often could not qualify for an adult psychiatric residential group home. Typically, they were told that they were not chronically mentally ill enough, were too immature, non-compliant with medications, or too aggressive to fit in the milieu for an adult group. Community residences for these youth at times depended upon the availability of public housing. Coordinating services for a youth with a qualifying disability who is leaving the child serving mental health system and transitioning into the adult mental health system has been difficult for our clients. CRSA's staff found that the most help in these situations came from the child's school if a good transition plan had been previously coordinated with the youth's community providers. One state wide community services provider we especially found helpful to qualifying youth, was the Illinois Centers for Independent Living, CIL.

### HFS BEHAVIORAL HEALTH PROGRAMS:

During FY19, the CRSA Regional Coordinators continued to focus attention and discussion on the changing community-based service systems and emergent populations of youth and families who did not completely meet or understand how to access state funded local mental health services. CRSA staff successfully linked families to resources as standard operations, however families voiced additional confusion regarding the statewide changes in Medicaid as the conversion to managed care was emerging. Support lines are anticipated for FY 2020 to help families successfully transition to their MCO's.

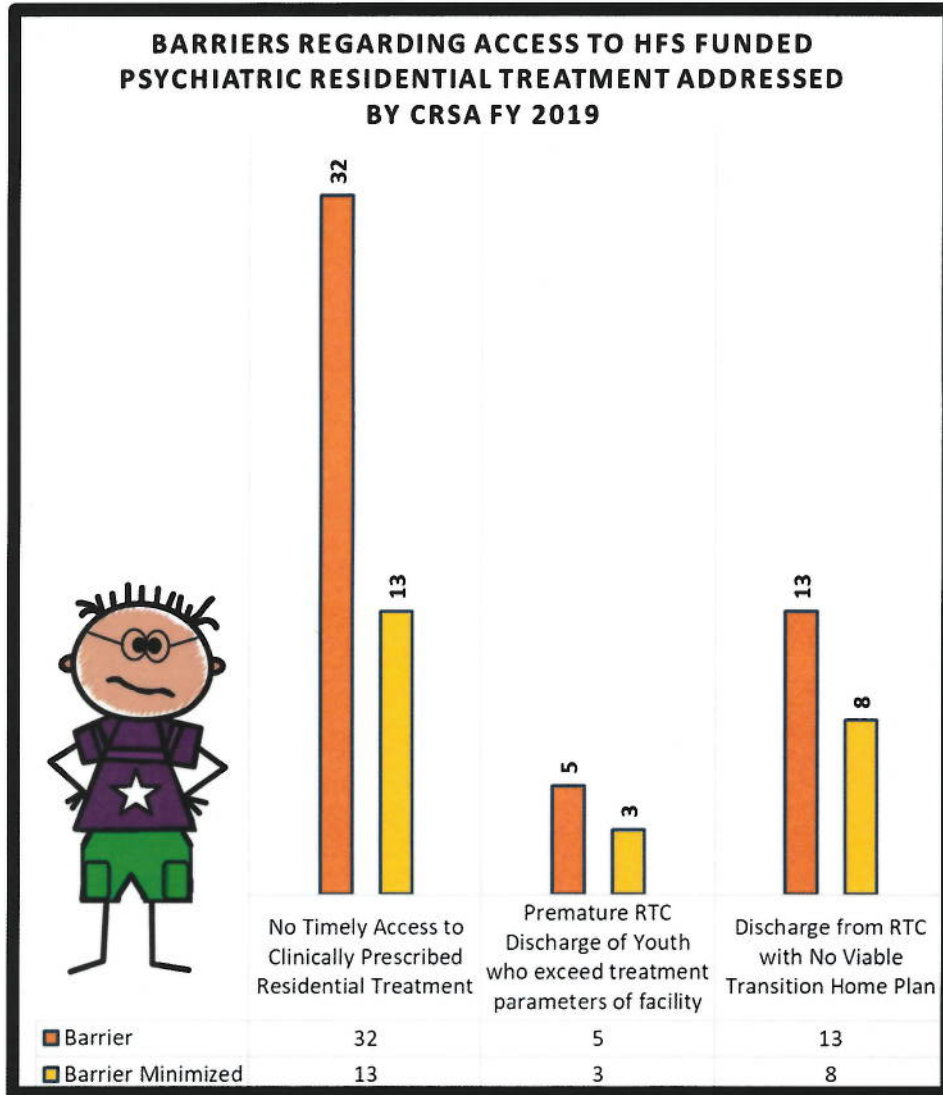
**The Family Support Program:** In 2017, the Individual Care Grant (ICG) Program aka Rule 135 was converted to the Family Support Program (FSP) aka Rule 139. The ICG had historically been a vital staple for children with mental illness and their families to obtain "non-means based" public funding for youth needing mental health treatment. At the end of FY17, the legislature moved the ICG program and its funding from the Department of Human Services (DHS) to the Department of Healthcare and Family Services (HFS). HFS reduced critical administrative barriers to the ICG application process. In the Spring of 2018, HFS introduced the Family Support Program application online. This improved access for families to apply for the FSP grant however we discovered that some minimally staffed mental health agencies struggled with timely completion of the required evaluation called the IM+CANS. <sup>2</sup>The Illinois Medicaid Comprehensive Assessment of Needs and Strengths (IM+CANS) is a unique model for integrating assessment and treatment planning into a single process, built for Illinois in consultation with Dr. Lyons and his team, and with input from state agency partners. The comprehensive IM+CANS is a lifespan tool that provides a standardized, modular framework for assessing the global needs and strengths of individuals who require mental health treatment in Illinois.

HFS/FSP funds residential placement and community support services. CRSA received 79 requests for assistance with accessing FSP services for youth. We successfully facilitated the resolution of 58 of those cases. The remaining cases either did not qualify for FSP or the family chose another service.

This fiscal year CRSA Coordinators noted that residential treatment facilities had extensively long waiting lists for admissions. In essence, youth could have full funding for residential treatment yet not have timely access due to the lack of available facilities appropriate to treat the youth's presenting conditions. The most difficult to place youth were those who presented with complex treatment needs such as severe mental health issues, behavioral problems, coexisting developmental disabilities, juvenile justice histories and or other health impairments.

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<sup>2</sup> [https://socialwork.illinois.edu/about-ssw/engagement-initiatives/im-cans/?doing\\_wp\\_cron=1586280334.7399868965148925781250](https://socialwork.illinois.edu/about-ssw/engagement-initiatives/im-cans/?doing_wp_cron=1586280334.7399868965148925781250)

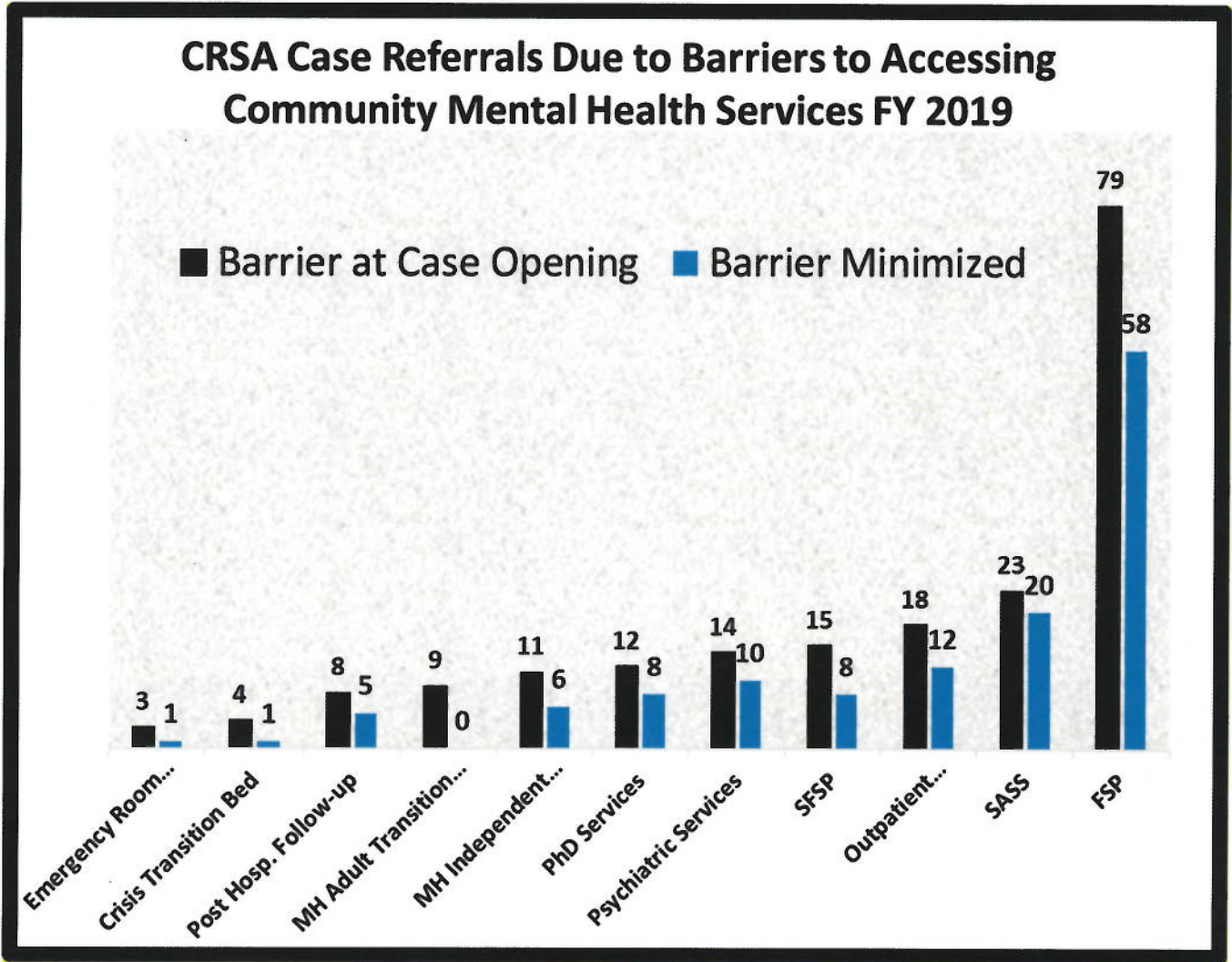


**Outpatient Community Based Counseling:** CRSA Regional Coordinators continued to observe that intensive outpatient therapy and case management services delivered in the youth’s home or community more than once a week were seldom available to that intensity. Youth whom CRSA served who had existing local mental health services at intake, typically were not receiving intensive outpatient community based counseling. Although several reforms for outpatient community stabilization services for youth were well described in the Community-Based Behavioral Services (CBS) Provider Handbook Illinois Department of Healthcare and Family Services these reforms were not yet fully implemented this fiscal year.

In FY 19 CRSA received 18 requests for assistance obtaining intensive outpatient services. We were successful in coordinating access to community based counseling services for 12 of those youth, but those services were not intensive counseling services.



Access to outpatient Psychiatric services was a barrier to 14 youth served by CRSA. Regional Coordinators were able to resolve 8 of those cases. <sup>3</sup>The lack of child and adolescent Psychiatrists and outpatient counselors is listed as an ongoing problem in Illinois. The number of behavioral health care professionals needed to remove the shortage designation in health professional shortage areas is high in all states surrounding Illinois, especially in rural areas. However, Illinois has seen the highest increase in these shortages between 2017 and 2018.



<sup>3</sup> THE COST OF MENTAL ILLNESS: ILLINOIS FACTS AND FIGURES Hanke Heun Johnson, Michael Menchine, Dana Goldman, Seth Seabury May 2018

Specialized Family Support Services (SFSP) as related to custody relinquishment of youth in Psychiatric crisis: A lockout is a situation in which a youth's parent refuses to allow him/her to return home upon discharge from a psychiatric hospital or residential treatment facility, or a situation in which a parent refuses to pick up the child from a facility, and has refused or failed to make provisions for an alternative living arrangement<sup>4</sup>. Custody relinquishment comes with great stress as families feel forced to consider giving up guardianship of their child with mental illness in order for that child to get state-funded psychiatric treatment. In addition, custodial relinquishment can occur when parents have safety concerns when their psychiatrically unstable child threatens to harm themselves, siblings, family members, classmates and or community members.

Regarding referrals involving active psychiatric lockouts and the resultant custody relinquishment risk in FY 18 we served 14 families struggling with custody relinquishment risks. This fiscal year 2019, CRSA had 12 cases presenting with a psychiatric lockout custody relinquishment risk.

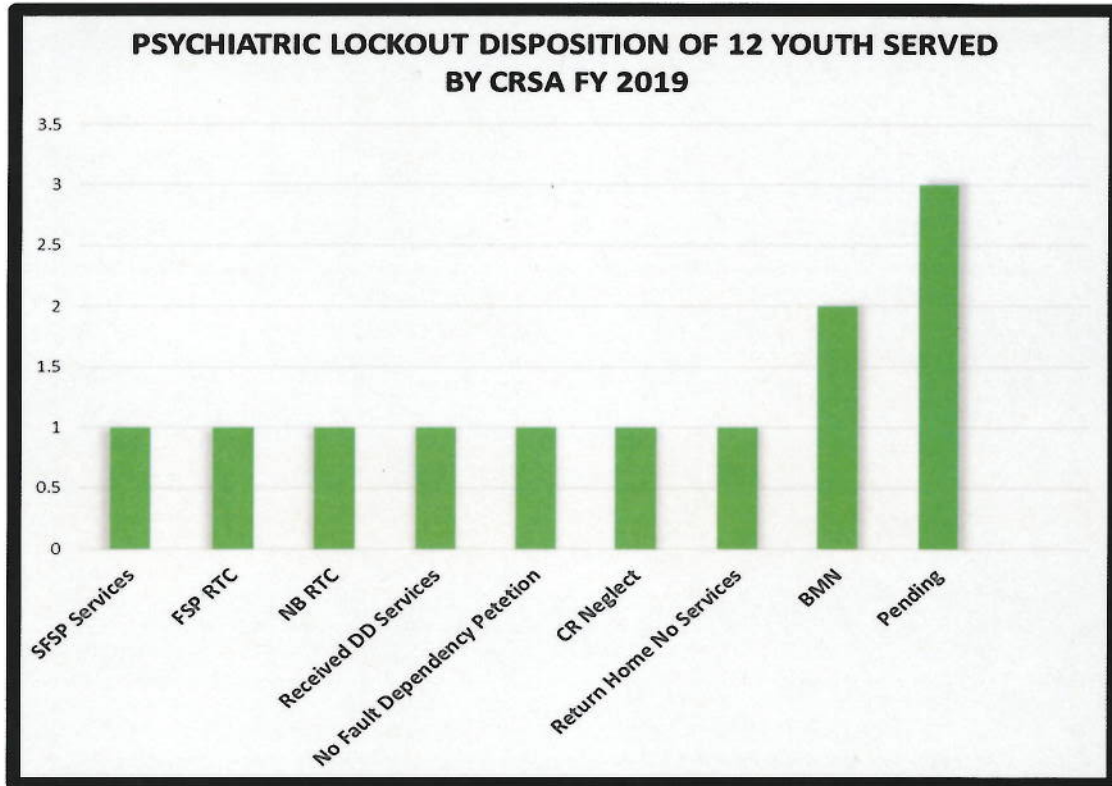
The implementation of <sup>5</sup>PA 0808 and the HFS initiation of the Family Support Program, Specialized Family Support services (SFSP) had some glitches for CRSA clients. Both were written to assist families with additional supports to help them obtain intensive services for their youth with severe mental health and behavioral conditions. SFSP implementation seriously lacked available temporary transitional beds for the population of youth who could not physically return home directly from the hospital and it was difficult to successfully advocate for this population on our caseload. CRSA staff were told by families in this situation that they could not benefit from SFSP because they were not offered interim placement options for their child. Parents stated, and CRSA confirmed, that unless parent/guardian's signed a document that they would take their child home from the hospital they could not receive any SFSP services and that there were no interim placements yet developed by HFS as required in PA 0808. Parents with other children in their home, stated that they were in a "catch 22". All of the families we served explained their youth with severe aggression was a threat to the other siblings or elderly family members in their homes. They stated that they feared repercussions from child protective services if they put their other children at risk of harm by allowing their child with aggression back home. They stated that they wanted an interim place for their child to go from the hospital back home or from the hospital straight into a prescribed residential placement. Therefore, without the option for an interim bed as stated in PA 0808, these families struggled with maintaining guardianship. If best practice protocols are established and followed, less custody relinquishments for youth state-wide are expected. <sup>6</sup>Senate Public Act 100-0978 also adds additional protocols which if implemented will improve access to interim beds for youth awaiting admission to a residential treatment center or who require intensive home based supports before they can safely return to their families.

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<sup>4</sup> <http://www.whittedakifflaw.com/>

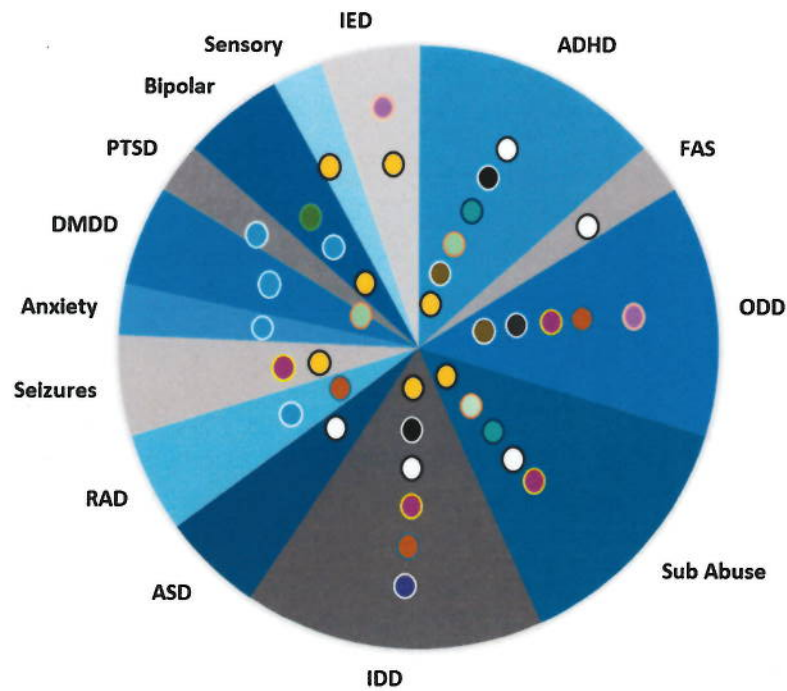
<sup>5</sup> <http://www.ilga.gov/legislation/publicacts/fulltext.asp?Name=098-0808>

<sup>6</sup> <http://www.ilga.gov/legislation/publicacts/100/100-0978.htm>

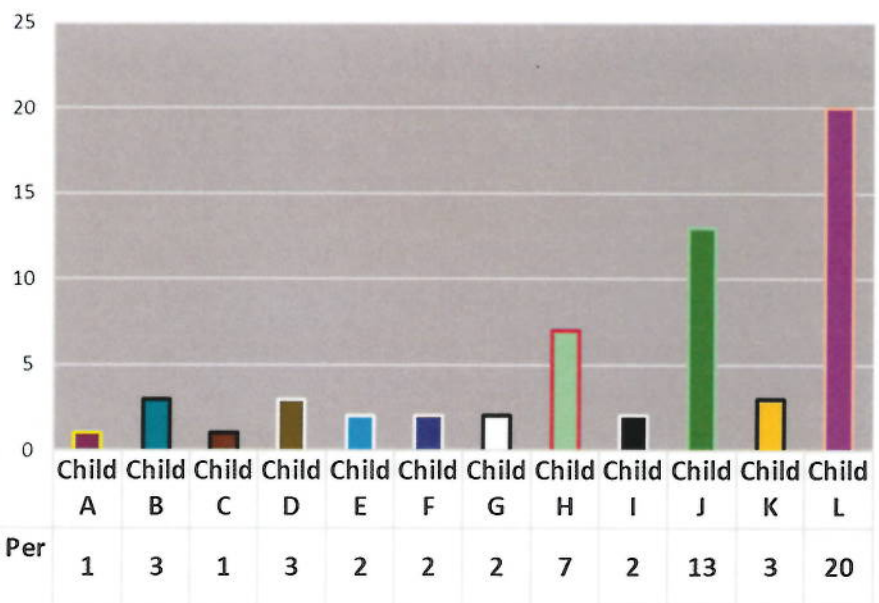


- **Custody Relinquishment:** Youth had FSP funding for residential treatment but no HFS funded facility would take this Youth.
- **Custody Relinquishment Neglect:** Youth had FSP funding for residential treatment, but no HFS facility would take the youth. Parents did not pick their child up from the psychiatric hospital and were charged with neglect.
- **No Fault Dependency Petition:** Parent could not qualify for SFSP because they could not take their youth home from the psychiatric hospital. No Transition beds were offered. They were coached to lock out their child to get a no-fault dependency petition in order to obtain residential treatment through DCFS for their child.

### DIAGNOSIS OF YOUTH AT LOCKOUT RISK SERVED BY CRSA FY 2019



### 12 CHILDREN PRESENTING AS A LOCKOUT RISK SERVED BY CRSA FY 19



Number of Hospitalizations Per Child

**Implementation of the N.B. Class action lawsuit:** N.B is a class action lawsuit pertaining to Illinois' failure to provide Early Periodic Screening Diagnosis and Treatment (EPSDT). On January 16, 2018, a Class Action Settlement (Consent Decree) was entered in Federal Court in Chicago, Illinois. N.B. v. Norwood, Case No. 11-6866. It concluded that all persons under the age of 21 and are Medicaid eligible in the State of Illinois, who have been diagnosed with a mental health or behavioral disorder or developmental disability and who have received a recommendation for intensive home or community base services to address their disorders, are entitled under the court settlement to receive these home or community based services. This includes access to Psychiatric Residential Treatment Centers (PRTF's). In June 2018, John O'Brien was court appointed as the expert to oversee the implementation of the NB consent decree. All parties are working on a plan that will meet the EPSDT objectives of the lawsuit. At the end of 2019, no formal plan has been publically implemented. Access to PRTF's has been a result of immediate relief for class actions members.

**The 1115 Waiver approval:** In May 2018, the Illinois Department of Healthcare and Family Services received approval of its 1115 waiver. This waiver includes pilots designed to better serve Medicaid beneficiaries in need of behavioral health services. It was anticipated by CRSA staff that this waiver would be implemented in 2019 to support improved access for youth with high acuity mental health needs to get access to more intensive stabilization and counseling services. The waiver authorizes the state to receive federal financial participation (FFP) for a continuum of services to treat addictions to opioids and other substances, as well as, other behavioral health conditions. The programs and related innovations are known as the Better Care Illinois Behavioral Health Initiative.

The HFS Intensive In-Home services pilot may be a key component of the Better Care Illinois Behavioral Health Initiative. This particular pilot is designed to offer in-home, team-based, clinical and supportive services to children ages 6-21 with complex behavioral health needs.<sup>7</sup> CRSA staff anticipate these intensive clinical services, if implemented, will assist in the stabilization of youth who previously may have been referrals to CRSA for residential care funding resources. As of the end of FY 2019, CRSA staff have not had any cases involved in the pilot.

## DEVELOPMENTAL DISABILITY SERVICES

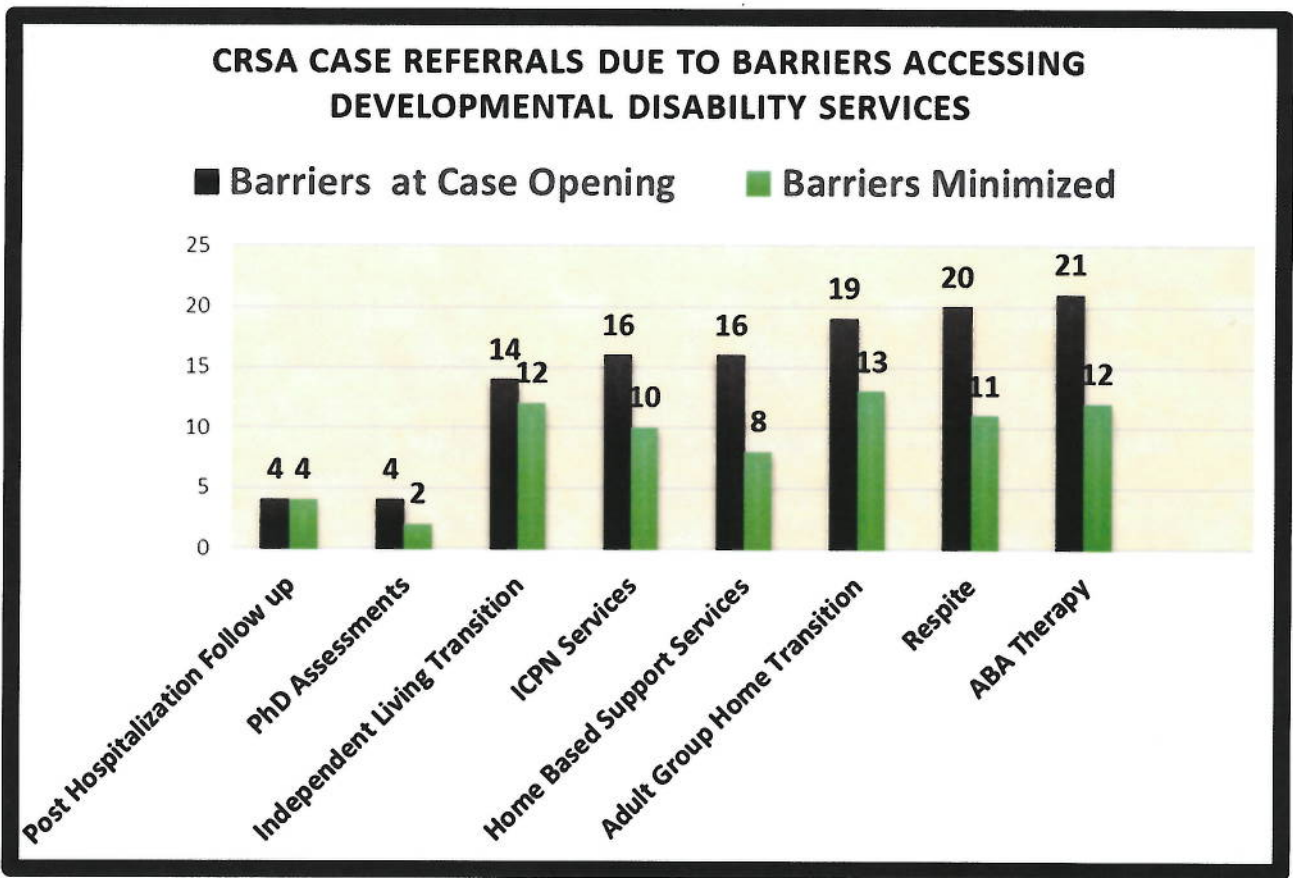
**Intellectual Developmental Disability (IDD) Youth:** The Department of Developmental Disabilities (DDD) in Illinois operates HFS Home and Community Based Services Waiver Programs called the Home and Community Based Services Support Waiver for Children and Young Adults with Developmental Disabilities. This waiver and is not intended to be an immediate post-hospitalization stabilization service. The waiver is for children and young adults with developmental disabilities ages three through 21 who live at home with their families and are at risk of placement in an Intermediate Care Facility for persons with Developmental Disabilities. Support services teams (SST) through DDD are typically available to children who have already been chosen to receive the Children's In-Home Support waiver. SST services are not automatically allocated to Medicaid eligible youth with IDD post psychiatric hospitalization. In short, parents report to CRSA staff that their youths with IDD who were at risk of entering or have entered psychiatric hospitals, receive little to no post hospitalization follow up supports unless they have met the selective and intensive criteria for SST services or have access to additional DMH/DDD home

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<sup>7</sup> <https://www.illinois.gov/HFS/Pages/default.aspx>

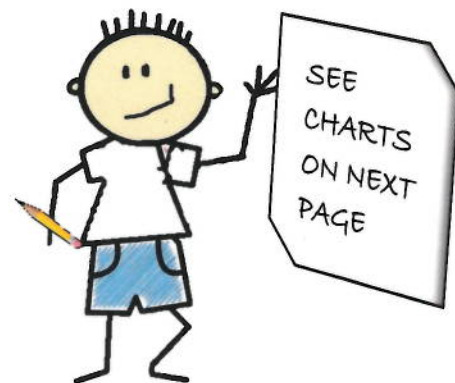


based supports. CRSA finds that families that contact us are often not aware of the avenues to seek these intensive services. DDD administration has been extremely helpful to the families for which CRSA advocated. Ten youth out of 16 that were presented to DDD through CRSA advocacy were given SST services to stabilize and support a plan of care. The other 6 youth referred to CRSA were given different services or the parents failed to engage in the pursuit of other options.



Children on the Autism Spectrum: Regional Coordinators became concerned that youth with Autism were not receiving access to recommended treatment in community settings. 30% of the

referrals to CRSA for FY 2019 were for children diagnosed with Autism Spectrum Disorders (ASD). Children with ASD were reported by CRSA Regional Coordinators to be notably underserved in the area of early interventions and or intensive in home behavioral supports. It was quite difficult to find a funder, private or public, that would pay for evidenced based <sup>8</sup>Applied Behavior Analysis (ABA) in the child's home. ABA is a type of therapy that focuses on improving specific behaviors, such as social skills, communication, reading, and academics as well as adaptive learning skills, such as fine motor dexterity, hygiene, grooming, domestic capabilities, punctuality, and job competence. Best practice statistics indicating that early intervention with children that have Autism produces a better therapeutic benefit than interventions later in childhood. "Early interventions not only give children the best start possible, but also the best chance of developing to their full potential. The sooner a child gets help, the greater the chance for learning and progress. In fact, recent guidelines suggest starting an integrated developmental and behavioral intervention as soon as ASD is diagnosed or seriously suspected."<sup>9</sup> CRSA receives cases for youth with Autism generally several years after their first diagnosis. Children with ASD who require residential Services are placed for various reasons. Most of which are a result of little or no early interventions.

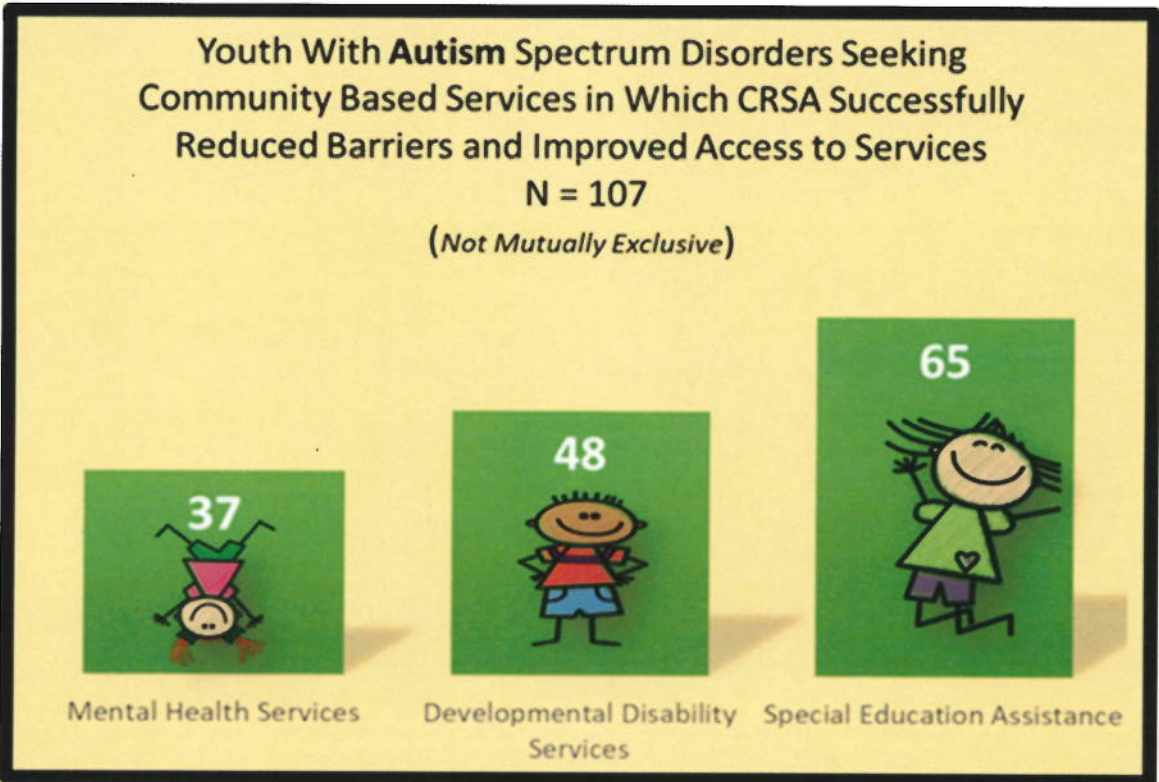
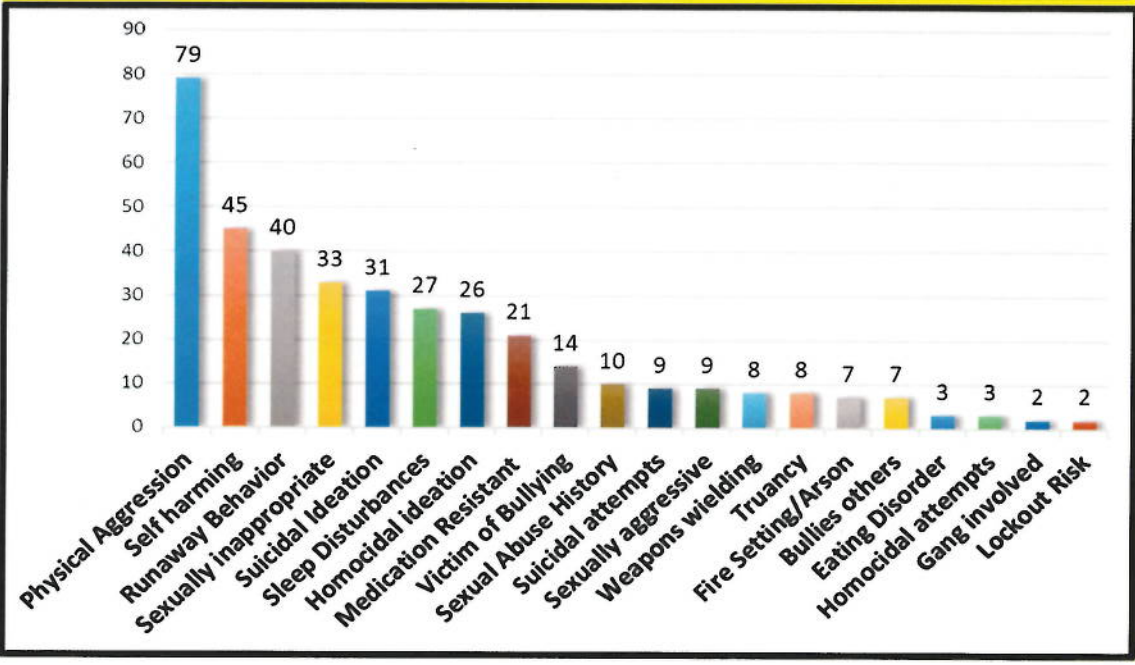


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<sup>8</sup> <https://www.psychologytoday.com/us/therapy-types/applied-behavior-analysis>

<sup>9</sup> <https://www.nichd.nih.gov/health/topics/autism/conditioninfo/treatments/early-intervention>

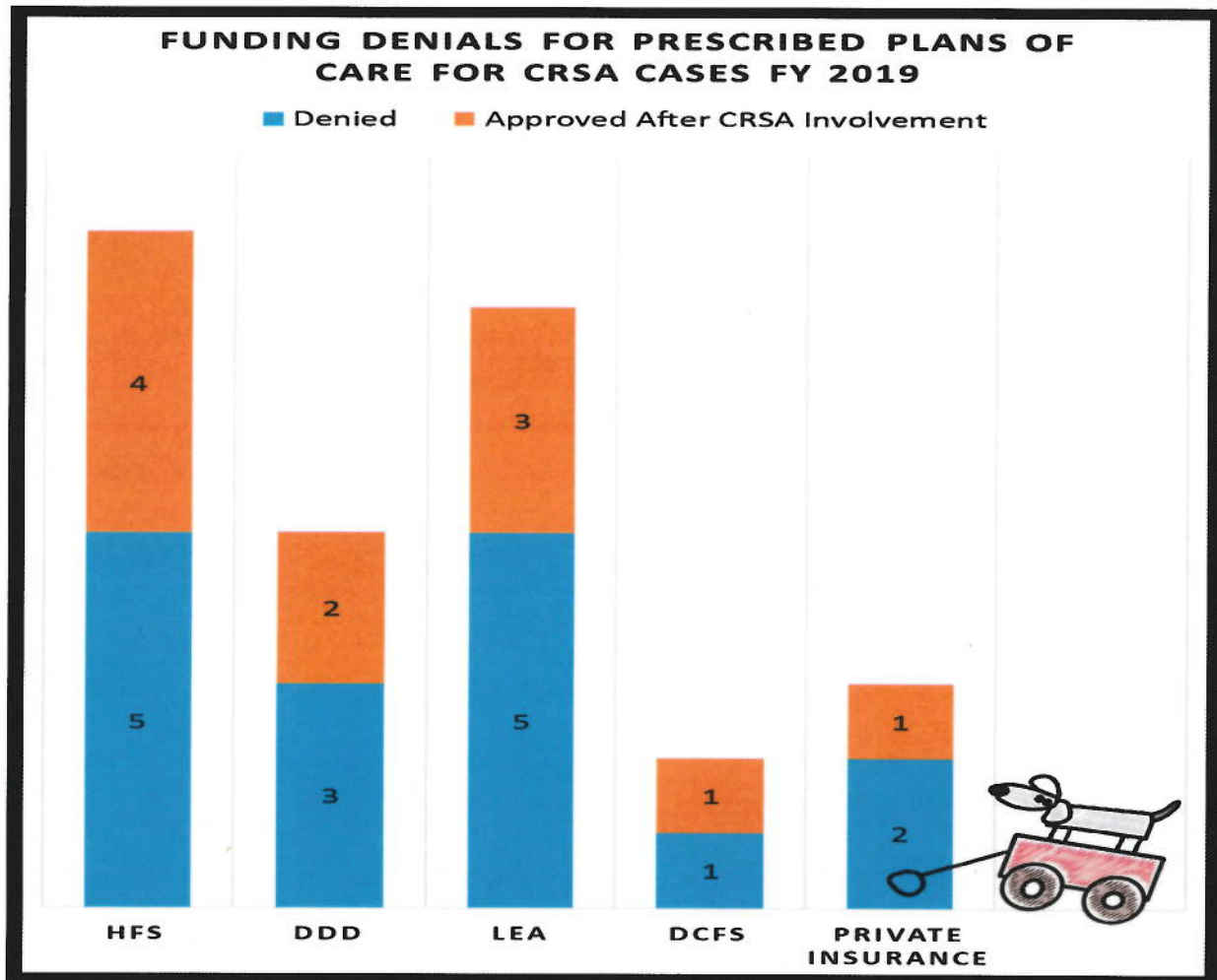
### Difficulty of Care Factors of Youth with Autism Referred to CRSA FY 2019





CROSS AGENCY FUNDING DENIALS FOR PRESCRIBED PLANS OF CARE

CRSA facilitated access to overcome funding denials for youth involved with HFS, DDD, Schools/LEAs, DCFS and Private Insurance. CRSA involvement in reducing access barriers in funding needed services was better than 50% successful.



## FISCAL YEAR 2019 ACTIVITIES

The CRSA board held five full board meetings during FY 19 that focused on promoting and implementing the concepts advanced in CRSA Strategic Plans in addition to providing technical assistance and carrying out dispute resolution responsibilities.

During FY 19, CRSA staff directly participated in 228 client progress meetings, school special education conferences and multiple-agency planning teams. The Executive Director and three, full time CRSA Regional Coordinators participated in 112 activities with agencies, organizations and groups and maintaining liaison relationships with statewide planning groups. Such groups include the Attorney General's Special Education Committee, the Children's Behavioral Health Association, the Mental Health Summit, Community Behavioral Health Association, St. Clair County Youth Council, and the DCFS Immersion Site Stakeholder meetings just to name a few.

## REPORT ON OBJECTIVES FOR FY 19

This year again ushered in new board members and said good-bye to some long standing board members.

The CRSA board is a diverse mix of experienced, well accomplished, legislative, community, parent and state-agency leaders. CRSA has a wide universe of knowledge to utilize as we address the objectives set forth in the CRSA legislation. This year the CRSA board and staff used their collective expertise to redesign the strategic plan which will support initiatives that significantly impact youth services in Illinois. The new CRSA Mission and Vision were listed in the front of this document.

CRSA staff and board completed the following objectives for FY 2019:

- CRSA monitored and objectively comment on legislative changes that significantly impact the CRSA service population.
- CRSA staff embarked on an aggressive campaign to reach out to neighborhoods and communities and organizations that serve like populations.
- CRSA tracked new data sets regarding our service population in order to better asses the challenges that face children and families who struggle with mental illness and co-existing disorders such as Autism and Developmental Disabilities.
- CRSA compared the incidence of school safety and mental health issues for referred youth.
- CRSA tracked the impact of video games and video gaming addictions on physical aggression in youth who are referred for assistance however the data was new to our intake which produced low numbers at this time.
- CRSA staff served on statewide non-partisan coalitions and committees to assist communities and agencies in developing services that improve the lives of children with mental health conditions in Illinois.
- CRSA worked with DoIT to improve data tracking from Excel to an interactive data base to improve our ability to adequately track trends in real-time for the board, legislators and the general public.
- CRSA proactively assisted parents in understanding the implementation of the HFS mental health programs geared toward our service population.



## CONSUMER SATISFACTION SURVEY'S

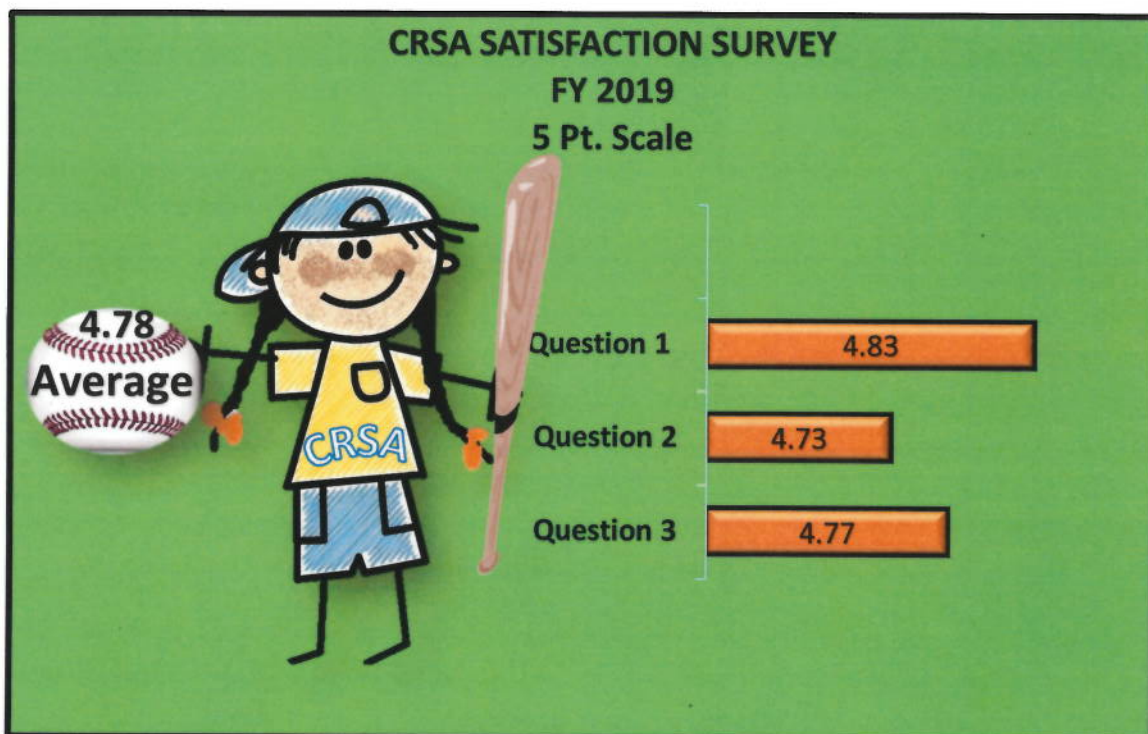
The consumer satisfaction survey is a questionnaire consisting of three simple questions scored on a one to five scale -- five being the highest rating and one being the lowest rating. The survey is distributed to every referent approximately 30 days after the date of referral with a self-addressed stamped envelope to maximize returns.

CRSA received close to 25% returned surveys this fiscal year which is a significant improvement over last fiscal year of only 12%. Responses indicate the levels of satisfaction with:

**Question 1: Was the Community and Residential Services Authority prompt in acting on your request for assistance?**

**Question 2: Were your ideas treated with respect?**

**Question 3: Were you satisfied with the services you received from CRSA?**



## TESTIMONIALS FROM CRSA CLIENTS

*CRSA spent hours on the phone working  
with me through everything I needed to  
know.*



*The CRSA Regional Coordinator was amazing in all her work with my family.*

**We always share contact info of CRSA with families who are needing support.**

*CRSA spent hours on the phone working with me through everything I needed to know.*

*I have been empowered even more with the representative on board. There is a sense of security knowing someone is there with information to aide my situation knowing the law and format.*

*The CRSA Regional Coordinator was very attentive when I asked for his help with my child's IEP. The CRSA Regional Coordinator helped me understand what to say during his IEP.*

*CRSA Regional Coordinators are very helpful, always friendly and respectful.*

*Great! CRSA was very nice and very helpful.*

*I so appreciated The CRSA Regional Coordinator and her support.*

*The CRSA Regional Coordinator has been **extremely helpful**. I would not have gotten our daughter the treatment she needs without her help!*

**VERY INSIGHTFUL AND HELPFUL.**

*We were able to get attention to the needs of our student that for past approaches had not been acknowledged or grated, the student is functioning better academically and socially due to CRSA's help and guidance. Thank you.*

*The CRSA Regional Coordinator is always there when I need help with everything regarding my child's district.*

*Thankful for all of The CRSA Regional Coordinator's help and support.*

*Thanks so much for getting an IEP evaluation set up with my child's school.*

*Very kind, very helpful and engaged with finding solutions.*

*The CRSA Regional Coordinator was very knowledgeable about the situation. If extra info is needed I could highly recommend CRSA.*

*The CRSA Regional Coordinator was wonderful.*

*The CRSA Regional Coordinator has been a blessing to our family in maneuvering through this complex system! We would recommend CRSA to anyone!*

*The CRSA Regional Coordinator was amazing. I truly appreciate his help and his advice. He listened very well to my concerns and helped me make a decision. I felt very comfortable and better equipped with him there. I couldn't be more grateful. Thank you so much.*

*The CRSA Regional Coordinator is extremely helpful. She is very knowledgeable and considerate. I'm so grateful to have The CRSA Regional Coordinator on my side as a resource.*

*They were very understanding. They know what I was going through.*

*CRSA has (and continues) to be a Godsend to my family. This is the second time they have been a positive advocate, and support team. My son's case is very unusual. The CRSA Regional Coordinator has given me faith and hope. No stone with her is left unturned!*

*Working through some issues now and hoping to get a resolution. It will be good to have CRSA help me figure out what is going on with school district and my son.*

*We learned a lot!*

*I feel good knowing that I can call for support in the future. I appreciate all the time The CRSA Regional Coordinator spent getting the details of the situation.*

*The CRSA Regional Coordinator helped our son who is doing great at his new school. It's almost like he is a different kid.*

*We worked with the CRSA Regional Coordinator and she did an excellent job. All of our questions were answered and we felt we had the highest support to successfully resolve our situation. We are very appreciative of The CRSA Regional Coordinator's leadership and guidance! Thanks!*

*The CRSA Regional Coordinator was polite, listened to my concerns, helped me get started in the right direction to help my grandson.*

*CRSA was very helpful in educating me on how to help a district seek an appropriate residential placement.*

*Very glad that the helpful lady, The CRSA Regional Coordinator, though couldn't come to IEP, was able to be on the phone for my son's IEP conference!*

**THE CRSA REGIONAL COORDINATOR DID A GREAT JOB.**



Thanks!

*An amazing job at helping me understand my child's rights and ensuring the school gave him the "least restricted" and proper education in an improvement specific to his needs.*

*She took time to talk to me and I felt very comfortable discussing my son's issues. Wonderful services. If not for your services, my child would be limited in his education and growing abilities. Thank you for ensuring the best choices to our family and child become the very best they can.*

Thanks!

*Very satisfied. Thank you.*

*Great service! Kept me from losing hope with my school district last year. Needed the support a lot.*

*Thank you for all the time and assistance given on the case.*

*Thank you for helping us advocate for our son!*

*The CRSA Regional Coordinator has been a Godsend to us. She has been a pillar of strength and wisdom. I completely trust her with my son's educational future. I cannot thank The CRSA Regional Coordinator enough for her hard work.*

*I was extremely happy and grateful for all the help we received to help our son.*

*Thank you The CRSA Regional Coordinator for not leaving our family alone in this journey.*

*The CRSA Regional Coordinator, I appreciate all your info in helping guide us to help our son.  
Thank you very much.*

*My experience overall was outstanding from my first call to the CRSA Office Manager to all the help from The CRSA Regional Coordinator. I have never received so much support and assistance from anyone in the 6+ years I had tried to get my son an IEP and an education he deserved. The CRSA Regional Coordinator, was amazing in so many ways, from the phone calls backing me away from the ledge, to the unlimited amount of support you gave me not only sending me links and information to educate myself to being there with me at every meeting. It was a great experience and I feel with the Regional Coordinator's knowledge and expertise, she is a valued asset to CRSA department.*

*The CRSA Regional Coordinator was very professional and helpful in taking time to discuss all my questions in detail. She provided assistance and will continue to do so in the coming school year with IEP and medical referral resources and assistance. Thank you!*

*The CRSA Regional Coordinator was very thorough and caring. We really appreciate her concern for our situation. Thank you.*

*I am thankful for the insight that CRSA representative gives me.*

*The CRSA Regional Coordinator is extremely patient, understanding and helpful.*

*The CRSA Regional Coordinator provided me with more information, resources and greater understanding of the IEP process and what parents can do than my \$300 per hour lawyer. I wish I knew about this program a year ago. The CRSA Regional Coordinator is fabulous and so supportive!!*

*Appreciated their ability to be at the meetings, quick response to questions through emails and calls during a very stressful time.*

*Really helpful. Thank you so much for your help and support.*

*The CRSA Regional Coordinator was wonderful to work with-easy to reach and talk to.*

*The CRSA Regional Coordinator and several other people were very helpful in explaining what I would need to fill out.*

*The CRSA Regional Coordinator was very knowledgeable and understanding. She is very caring, dedicated, wonderful addition. She has answered, come up with ideas, and has had advice, and researched and helped as much as she could. We think she is wonderful, caring and has a lot of information and helped many times with a positive attitude and always listens. From a parent raising a child that has been abused as a small child, before we adopted her. She is seventeen and the challenges are different but still there. When the child is on the borderline of PUNS, the help is not there. We have hit our heads many times trying to find solutions and sometimes, someone just to listen and offer solutions that at the time you cannot think of or your mind is so full of dealing with the child behavior you are unable to think forward. The CRSA Regional Coordinator has always been so helpful, sometimes it is listening and sometimes it is her power and who she knows that is helpful. We are holding our own for now. Each day is a challenge and would not have made it this far if it wasn't for the help we have had and support. The CRSA Regional Coordinators and their consultant are very wonderful, caring ladies and I am so touched by their kindness.*

*Thank you.*

