

Policy Brief

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Citizens for Missouri's

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Children



Children's Mental Health: Missouri Moves Toward a Comprehensive System

"The burden of suffering experienced by children with mental health needs and their families has created a health crisis in this country. Growing numbers of children are suffering needlessly because their emotional, behavioral, and developmental needs are not being met by the very institutions which were explicitly created to take care of them"

—Surgeon General's Conference on
Children's Mental Health:
A National Action Agenda.

Seeking appropriate mental health services for children is a difficult, if not impossible, task for many Missouri families. Too often it leads them to consider giving up custody of their children to the state in order to access services.

Parents should never be asked to choose between getting mental health treatment for their child and retaining legal custody of the child. Yet for at least 20 years they have been asked to do just that. Today, in half of the states almost one in four families seeking mental health care for a child face such an inhumane choice.

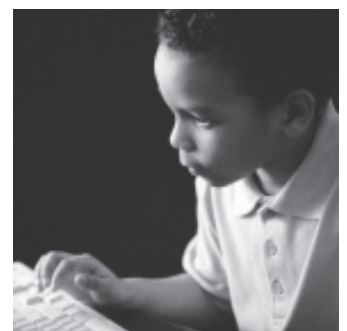
Prevalence of Mental Illness in Children

Childhood is typically thought of as a joyful, unburdened time in life, but for many

children, mental illness may destroy that happiness. The presence of a mental illness can be debilitating and can severely lower the quality of life for a child. Children with mental illness are at much greater risk of dropping out of school and of not being fully functional members of society in adulthood.

Figures on exactly how many children suffer from a mental illness vary by age group and by level of impairment from minimum to severe. Current data show that:

- **Almost 21% of U.S. children ages 9 to 17** have a diagnosable mental or addictive disorder associated with at least minimum impairment.
- An estimated 11% of U.S. children ages 9 to 17 suffer from a major mental illness that results in significant impairments at home, at school, and with peers. This translates into 3.96 million youth.
- 8.2% or 4.2 million children ages 5-17 have a reported mental/emotional problem and/or a functional limitation.





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Mental Health Service Use

Children with mental illnesses often require medication, intensive therapeutic intervention, parental support, and even hospitalization or residential treatment to address pervasive problems. More than 1.3 million children under the age of 18 – or one out of 50 – received mental health services in the US during 1997. Overall, children and youth under age 18 accounted for the largest percentage (40%) of persons under care for specialty mental health services in residential care programs. The World Health Organization reports that by 2020, childhood neuropsychiatric disorders will rise by over 50%, internationally, to become one of the five most common causes of morbidity, mortality, and disability among children. Suicide is the third leading cause of death among youth aged 15-24, and fourth among those ages 10-14, with the rate of teen suicide having tripled since the 1950s. In Missouri in 2003, 18 children died of self-inflicted injuries.

The Scope of the Problem in Missouri

In Missouri, roughly 7% (51,000) of youth age 9-17 are estimated to suffer from a serious emotional disturbance. This is defined as a functional impairment that substantially interferes with or limits the child's role in school, family, or community activities. In 2002, more than 36,000 Missouri children received public mental health services either through the Department of Mental Health (DMH), local school systems, or Medicaid.

How Many Children Are in State Custody for Mental Health Needs Only?

A recent General Accounting Office (GAO) survey of child welfare directors in 19 states and juvenile justice officials in 30 counties reported that, in fiscal year 2001, parents placed over 12,700 children into the child welfare or juvenile justice systems so those children could receive mental health services. About 3,700 of those children entered the child welfare system and approximately 9,000 entered the juvenile justice system. This number is doubtlessly much higher nationwide as the GAO did not receive data from 32 states –

including the 5 states with the highest population of children – and there was limited surveying of county juvenile justice officials. No federal agency formally tracks these children or maintains data on their characteristics and only a handful of states have begun to identify those children in custody for mental health needs alone.

In Missouri, approximately 600 children were identified, as being in the custody of the child welfare system for mental health needs alone as of November 2003. Missouri has not yet begun to identify the number of children in the juvenile justice system for mental health needs alone, although the GAO survey found it to be much greater.

A National Alliance for the Mentally Ill (NAMI) survey of families with children who have a mental illness, found that 23 percent of respondents reported having been told they will have to relinquish custody of their children to get needed services, and 20% said that they did so to get care. Other parents were encouraged to call the police and turn their children over to the juvenile justice system to get mental health care. More than one-third – 36% – of respondents reported that their children were placed in juvenile justice facilities because needed services were not available.

Why Do Placements Occur?

Seeking appropriate mental health services for children is a difficult, if not impossible, task for many families. The GAO reports that officials in the states surveyed noted that those children in custody came from families of all financial levels suggesting that a variety of factors influence whether parents relinquish custody of their children to receive mental health services for them. Here are the general reasons why parents often turn to state custody to access mental health services for their kids:

1. Parents often quickly exceed the mental health benefit limits of their private health insurance plans. Many private insurance plans have limited coverage for traditional psychotherapy treatments: usually a set number of sessions; limited in-patient hospital

days; and many do not cover residential treatment placements at all. Parents are forced to pay for the treatment out-of-pocket. However treatment is generally long-term and quickly becomes prohibitively expensive.

2. Even when private insurance covers the cost of mental health treatments, some parents have trouble accessing treatment for their children because of a shortage of services and providers in their community. Shortages of child psychiatrists, child psychologists, behavioral therapists and residential facilities exist across the United States and, especially in rural areas. Children in the child welfare or juvenile justice systems receive preference for services, particularly when the services are court-ordered. Private insurance does not always cover a full array of intensive, community-based rehabilitative services that children with the most severe mental or emotional disorders need, while public health insurance programs do.
3. Parents' incomes are too high to be eligible for public health insurance programs – Medicaid and the State Children's Health Insurance Program (MC+ in Missouri).
4. Many parents who do qualify for public insurance programs such as Medicaid and MC+ have trouble accessing mental health services, because of a shortage of providers who accept public insurance patients. Low reimbursement rates to providers may restrict the participation of providers and therefore restrict services to families.
5. A significant number of children are uninsured (12% of all U.S. children and 6% of Missouri children) and have limited access to mental health services.
6. Budgetary shortfalls in many states as well as local school systems have reduced their ability to provide services to all the children who need them. The Missouri Department of Mental

Health's funding is only enough to serve about 20% of the children who potentially qualify for state-funded services.

Children's Mental Health Legislation, 2002-2004

For years, child mental health advocates have recognized the problem of parents obtaining needed mental health services for their children. Two surveys done in the late 1990s by the Research and Training Center on Family Support and Children's Mental Health and the National Alliance for the Mentally Ill began to describe the extent to which custody relinquishment was occurring. Two landmark reports, which more fully described the problem, were released in 2000.

The first report, titled "*Relinquishing Custody: The Tragic Result of the Failure to Meet Children's Mental Health Needs*" was released by the Bazelon Center for Mental Health Law. This report outlined the problems and possible statutory solutions to custody relinquishment and laid the groundwork for state advocacy efforts. Later that same year, the U.S. Surgeon General held a conference and released a report on "*Children's Mental Health: A National Action Agenda*".

In March of 2002, Citizens for Missouri's Children (CMC) released a policy report entitled "*A Choice that Parents Should Never Face: Relinquishing Custody of Their Child to Obtain Mental Health Care.*" This report received a good deal of media coverage across the state and brought the problem to the attention of the Missouri public and legislators. Many parents who had given up custody of their children began to share their stories with local newspapers, local television and radio stations.

One such family brought their story to the attention of Senator Mike Gibbons (R-15th District-St. Louis County). After other treatment options had failed, Beth and Michael Viviano's daughter, Mariana, needed residential mental health treatment services. The family was turned down by virtually every residential facility in the state and told by many people that if they



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relinquished custody of their daughter, a facility would have to accept her. They turned to Gibbons. He committed himself not only to figuring out how their child would receive the mental health services she needed, but also how all of Missouri's children with mental health needs would access services. In Gibbons, the Viviano family found "a hero" and the mental health community found a champion.

In the years 2002-2004, Senator Gibbons, as well as Senator Patrick Dougherty (D-4th) and Betty Sims (R-24th), and Representatives Roy Holand (R-135th), Jodi Stefanick (R-128th), Otto Bean (R-163rd) and others became important advocates for the legislation that sought to solve these problems.

In response to the report by Citizens for Missouri's Children and the needs of children and their parents around the state, Senate Bill 923 was passed during the 2002 legislative session. This legislation allowed a family to seek assistance from the court to obtain mental health services without being listed on the child abuse and neglect register. The bill enjoyed bipartisan support and was sponsored by Senator Betty Sims. This bill was considered a first step to reforming a flawed system.

In October 2002 a *Time* Magazine article profiled a Missouri family forced to relinquish custody of their child and outlined how the new legislation would change the problem. A full description of SB 923 is included in this brief.

The months following the 2002 legislative session were spent developing legislation that would create a comprehensive system of care for children with mental health needs. This legislation was introduced in the 2003 legislative session. It enjoyed bipartisan support as well and seemed to be moving through the legislature quickly. During that same time, reform of the foster care and child welfare system was receiving a great deal of attention. The Speaker of the Missouri House, Catherine Hanaway

(R-87th-St. Louis County) sponsored a bill to reform the foster care system. Late in the session the children's mental health system bill was amended to the foster care bill (HB 679), which passed in mid-May. However, this bill had some controversial provisions and Governor Bob Holden vetoed it. An attempt to override the veto failed. This meant the demise of the children's mental health bill for the 2003 session.

During the 2003 session, House and Senate leadership supported legislation (SB 266) that dealt with custody relinquishment. The bill passed unanimously in both the House and Senate. It mandated that DMH outline the costs of providing services to those children identified through SB 923 (those in custody solely for mental health needs) and to make recommendations regarding funding mechanisms by December 2003. This was yet another needed step towards determining how to fund a comprehensive children's mental health system so that all of Missouri's children who need mental health services can receive them.

The time between the 2003 and 2004 legislative sessions was spent fine-tuning legislation for the creating the comprehensive system. Revised legislation (SB 1003) was introduced at the start of the 2004 session. It was sponsored by Senator Gibbons and cosponsored by Senators Mary Bland (D-9th), Dougherty, Harry Kennedy (D-3rd), and Charles Shields (R-34). This bill also enjoyed broad bipartisan support and moved through the legislature quickly. The Senate unanimously passed the bill on January 22nd, 2004 and the House followed suit with unanimous passage on February 24th. It was the first bill of the session signed into law by Governor Holden, on March 10th. SB 1003 created the children's comprehensive mental health system. It also directed the Department of Social Services (DSS) - Children's Division to identify all children currently in custody for mental health needs alone and to create plans to move them back into the custody of their families.



Three Reports:

"Relinquishing Custody:
The Tragic Result of the Failure to Meet Children's Mental Health Needs"

"Children's Mental Health: A National Action Agenda"

"A Choice that Parents Should Never Face:
Relinquishing Custody of Their Child to Obtain Mental Health Care"

A family may seek assistance from the court to obtain mental health services without being placed on the child abuse and neglect register.



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SB 923

Voluntary Placement

SB 923 was the earliest of the three bills to become law. It mandates three changes to Missouri statutes regarding children's mental health and custody relinquishment.

- A family may seek assistance from the court to obtain mental health services without being placed on the child abuse and neglect register. Missouri statute now states that the court may obtain jurisdiction when "the child or person seventeen years of age is a child in need of mental health services and the parent, guardian, or custodian is unable to afford or access appropriate mental health treatment."
- SB 923 also allows the court to order that the child receive necessary services in the least restrictive environment (including home and community-based services, treatment and support), based on a coordinated, individualized treatment plan.
- The plan must be developed by the applicable state agencies and approved by the court. The family actively participates in the design of the service plan, which is to be submitted to the courts within 30 days of the court obtaining jurisdiction.

Implementation of SB 923

Although the passage of SB 923 meant that parents would not be listed on the child abuse and neglect registry, parents still lose legal custody of their children if they relied upon the court system to access mental health services. This prompted DMH and the Children's Division to develop custody diversion protocols to keep families out of the court system and to direct them to local community mental health centers. Through the use of the custody diversion protocols, parents would bypass the court system entirely and retain legal custody of their children.

The custody diversion protocols were launched in the 12th Circuit (Warren and Montgomery Counties) and the 21st Circuit (St. Louis County) in the summer of 2003. A second phase was launched in eight additional Circuits in the spring of 2004, where current "system of care sites" were in place. It is unclear when statewide rollout of the diversion custody diversion protocols will be fully completed although DMH is reporting another launch in the Fall of 2004 with full implementation by January of 2005.

CMC believes it is important to implement the custody diversion protocols across the state, so that parents will not continue to risk losing legal custody of their children. Currently, many circuits have little guidance on how to handle cases where parents are considering relinquishing custody solely to access mental health needs.

The custody diversion protocols are designed to make sure the appropriate agencies are contacted and conduct needed assessments. It is then the responsibility of these agencies to provide the needed services and supports to the family while allowing the parents to retain custody of their child.

DMH and the Children's Division report that local community mental health centers have received 28 referrals since the custody diversion protocols began in the 10 sites. At this time:

- 22 of the 28 youth have been assessed.
- 5 youth were placed in out-of-home treatment centers, and
- 17 received community mental health services.
- Only 2 of the youth were placed in Children's Division custody, 1 as a result of the parent wanting to relinquish permanent custody.



The second piece of legislation passed required DMH and DSS to prepare a joint plan to address the mental health needs of children in the custody of the Children's Division exclusively because of their need for mental health care.

CMC believes that the custody diversion protocols work when the local stakeholders have been trained and where adequate resources exist to provide services to youth with emotional disorders. A thorough evaluation and continual monitoring of the sites where the protocols are in place would help determine if they are really working. This has not occurred. It's also possible that other areas of the state utilize a similar set of procedures, but information is not being collected outside of the 10 sites. It's vital that the local community mental health centers, juvenile officers and Children's Division caseworkers in all 45 Circuits across Missouri are trained on how to use the custody diversion protocols and that a monitoring system is set up to track outcomes.

SB 266

Financing Mental Health Services for Children

The second piece of legislation passed required DMH and DSS to prepare a joint plan to address the mental health needs of children in the custody of the Children's Division exclusively because of their need for mental health care. Both departments are required to estimate the cost of providing services to these children. The plan also included an analysis of federal funding options, including possible Medicaid waivers the state could apply for. The report included an analysis of the feasibility and time frames of securing federal funds for support of mental health services and supports. The bill also attempted to estimate the larger future costs of providing services to any child who would come into the child protection system solely due to mental health needs. This report would provide direction in how to fund a children's comprehensive mental health service system. The plan was to be completed by January 1st, 2004, and submitted to the Governor, President Pro Tem of the Senate and the Speaker of the House.

Implementation of SB 266

Following passage of SB 266, a consultant was hired by DMH to evaluate the number of children who had been placed in the custody of the state solely to gain access to mental health services, and to make

recommendations for financing those services. In that report, Alicia Smith & Associates, LLC identified **296** children ages 3-17 that had likely entered foster care between January 1, 2002 and December 31, 2002 solely to access mental health services. The criteria for identifying these youth were as follows:

SB 266 children were ages 3-17:

1. For whom the following circumstances of removal were identified; child's behavior problem, child's disability, alcohol abuse (child), drug abuse (child), abandonment, or relinquishment and
2. Who were placed in an institutional setting within 90 days of being placed in state custody. Except when the circumstance was abandonment then the child had to be placed in an institutional setting on the date they were placed in state custody.

The following children were **not** counted:

3. Those with a substantiated report of child abuse or neglect within the year prior to state custody.
4. Those with a moderate or severe mental retardation disability.
5. Those who did not access mental health services within six months of being placed in state custody.

CMC believes that these criteria provide a conservative estimate. The report also stated "**It should be noted that the total number of SB 266 children is much greater.** As per the report, the Children's Division placement data indicates that there are approximately 600 children in state custody that meet the SB 266 criteria as of November 30, 2003."

The report estimated the costs to treat these children at approximately \$3,600 per child per month, or about \$43,000 per year in state and federal funds. This includes:

- out-of-home placement and related service costs including room and board
- Medicaid services including many mental health specific services including hospitalization and physical health services
- Services paid for by DMH including specialized mental health services, some case management, and certain forms of residential treatment.

The report outlined financing options and recommendations that the state could pursue to address both the children identified under SB 266 and, potentially, the development and implementation of the comprehensive children's mental health service system. The report concluded that two options made the most sense for Missouri.

- Implement the Voluntary Placement option under Title IV-E of the Social Security Act and
- Apply for a Section 1915(c) home and community based waiver under the Medicaid Rehab Option for those SB 266 children who are at risk of institutionalization and, potentially, for other at-risk children in the mental health system.

Voluntary Placement under Title IV-E

Voluntary placement allows a family to relinquish physical custody but retain legal custody of their children. These children become eligible for mental health services reimbursed by Medicaid and residential services that can be funded with Title IV-E funds which are matched by the federal

government at approximately 43 percent of each state dollar spent. Missouri has not explored this option in the past for fear of opening a floodgate of demand for services that the state could not afford. The report recommends that the state set eligibility guidelines in order to limit the total number served. This would allow the state to serve those children currently in the system for mental health needs alone, or for a set number of new children each year, but it would not solve the problem of financing a comprehensive system for all children. The voluntary placement only lasts 180 days and is meant to be a "respite" for parents. It does not solve the problem of long-term residential care. DMH is moving ahead with this option as a first step in providing services to a small subset of children. The option is estimated to be available by mid-2005.

During the 2004 session, voluntary placement agreements were written into statute with the passage of HB 1453, known as the foster care reform bill. A section of this bill described exactly how voluntary placement agreements would work between DMH, CD, and parents. The ultimate goal of voluntary placement agreements is for the parent, legal guardian, or custodian to maintain legal custody of the child while obtaining for the child the mental health treatment services they need. The state child-serving agencies as well as advocates led the effort to include this language in the foster care bill. Putting voluntary placement into statute ultimately gives parents more protection from the agonizing possibility of losing legal custody of their child.

1915(c) Home and Community Based Waiver

The 1915(c) waiver option would allow the state to offer an array of community based services to more children while receiving matching federal Medicaid funds. However, the federal government requires that children must be in need of institutional care before becoming eligible for the waiver services. They also require that the community services be no more expensive than the alternative institutional placement. Three states have used the 1915(c) waiver to expand community-based services.



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SB 1003 mandates that DMH, in partnership with all other child-serving departments, develop a unified, accountable, comprehensive children's mental health service system.

The waiver does allow the state to expand capacity without exposing them to unlimited financial pressure. It is also possible to expand the program, as state funds become available. It appears that this waiver could cover those children coming into state custody needing institutional care and could be a piece of the financing puzzle for the comprehensive system. DMH has set up a financing workgroup to plan for this waiver, which is apparently, relatively simple to prepare. DMH and the Children's Division are working toward an early 2005 submission date. Depending on the response by the federal government, implementation could begin in mid to late 2005.

Section 1115 Research and Demonstration Waiver Option

Even though the SB 266 report did not recommend the 1115 waiver as an immediate proposal, it did conclude that it might be the most viable option for funding a more comprehensive system of mental health services for children. It would give Missouri the maximum flexibility in waiving various federal Medicaid regulations allowing the state to design its own program. It would also allow the state to blend federal funding streams under all the titles in the Social Security Act providing more flexible and adaptive financing options. It would allow the state to include children in families with incomes above current Medicaid eligibility. It would enable the state to address the needs of children currently in custody and could also fund the comprehensive children's mental health service system.

One disadvantage is that the 1115 waiver requires a more restrictive budget neutrality test, meaning that the new program can not cost the federal government more than the old system did. The 1115 waiver applications are time-consuming and expensive to prepare and take much longer to negotiate with the federal government. It also requires real buy-in and commitment to total system reform. CMC feels that even with these disadvantages an 1115 waiver should be seriously considered as a way to finance the comprehensive system. The DMH financing workgroup is exploring this waiver option as well.

SB 1003

Children's Comprehensive Mental Health System

The most recently passed legislation, SB 1003, achieved three outcomes. First the bill establishes the groundwork for a comprehensive children's mental health service system. The law intends to create a system of mental health care for all of Missouri's children, so that no parent will have to relinquish custody of their child to obtain appropriate services. The bill mandates that a plan for the comprehensive system be submitted to the General Assembly and the Governor by December 2004. The following section of this brief more fully describes the characteristics of the comprehensive service system.

SB 1003 expands SB 266 by requiring Children's Division to again determine which children are in their custody solely due to mental health needs. Within 60 days of identifying these children, appropriate agencies and the family must develop an individualized service plan for each child, identifying which agencies will provide and pay for services, subject to appropriations. The plan must be submitted to family court for approval.

After the court approves a plan, the court may order the child returned to the custody of their parent, guardian, or custodian. This section of the legislation is intended to get children back into the custody of their families as soon as possible.

Finally, the bill also creates a new funding relationship between DMH and the Children's Division. After children return to the custody of their family and are being served by DMH, DMH can bill DSS for the cost of care pursuant to the individualized service plan and to the comprehensive financing agreement made by the two agencies.

Since passage of SB 1003, the Children's Division has identified 538 children who are likely in state custody due solely to mental health needs using three criteria, similar to the SB 266 criteria used in the Alicia Smith report:

1) conditions of removal, 2) a residential treatment or therapeutic foster care placement required within 90 days, and 3) no probable abuse or neglect finding. The Children's Division is now completing a case by case review of the 538 youth to insure that none of the 538 children are in custody for other reasons besides mental health needs. The Children's Division thinks it is possible the number of children in custody solely for mental health needs may be smaller than 538.

After completing each case review, appropriate agencies must develop individualized service plans within 60 days. Plans must be submitted to the court, which may order the child returned to the custody of the parent, guardian, or custodian. At this time no service plans have been developed nor have any children been returned to the custody of their families. The Children's Division reports that the case review and individualized service plan process will begin in the early fall of 2004 with the possibility of legal custody being transferred back to a few parents by the end of the year.

Elements of the comprehensive system

SB 1003 mandates that DMH, in partnership with all other child-serving departments, develop a unified, accountable, comprehensive children's mental health service system. The system is designed to build upon the current successful service systems, fill in the gaps in the current structure, and offer a full array of services to all Missouri families.

The goal of the comprehensive system is to ensure that every Missouri child who needs mental health services will receive them. The first step in reaching that goal is to develop a plan for the comprehensive system. The legislation called for the creation of two groups to guide the development of the plan. A Comprehensive System Management Team (CSMT) is comprised of all the child-serving departments as well as family-advocacy organizations and family members, child advocate organizations, and local members of organizations that serve children. The CSMT will oversee the development and implementation of the comprehensive system. The Stakeholder

Advisory Committee (SAC), comprised of system partners including private and not-for-profit organizations and representatives from local organizations, will provide input to the CSMT to assist the departments in developing strategies for implementation and that ensure positive outcomes for children are being achieved.

Next Steps

The CSMT and SAC were established in the spring of 2004. They will be responsible for developing the plan for the system, which is due to be presented to the Governor in December of 2004. Their work began in the early summer months with the draft plan to be completed by September 30th, 2004. The plan will be submitted to the Governor in December of 2004. There will be an opportunity for public feedback early in 2005. Full implementation of the comprehensive system is set to begin in 2005 with a focus on financing and appropriations during the 2005 legislative session. The key to fully implementing this comprehensive system will be finding the resources to pay for the services needed.

Statewide rollout of the custody diversion protocols is an immediate priority. It is also unclear how well the custody diversion protocols are working in the few sites where they are in place. It is important to evaluate how they are working so far, make corrections if needed, and roll them out statewide. CMC also feels that it is important to return legal custody to as many families as possible. CMC feels the state must be held accountable for the timely implementation of the new laws and must keep track of the children coming into custody for mental health needs alone to ensure that custody relinquishment does not continue.

All system partners are working hard to make sure parents have the options they need to meet their children's mental health needs and that families are receiving services in a way that puts themselves and their children at the center of services. It is imperative that Missouri invest in its young people so they can become competent and contributing citizens, employees, and leaders in the future of our state.

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Citizens for Missouri's Children is a statewide public interest organization. Its mission is to be a voice **for our children**, especially those with the greatest need.

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