



# Children's Mental Health A Family Guide

*Empowered  
Parents:  
Educated,  
Engaged,  
Effective!*

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## Introduction

We are families of children with special health care needs, including mental health needs. We are not here to tell you what to do with your child, because *you* are the expert on your child. We are here to support you in making important decisions to ensure that your child receives the services and supports needed for the best life possible.

Children's mental health, just like physical health, should follow the "medical home" model. A "medical home" is not a place, but an approach to care that ensures that care is:

- Accessible
- Family-centered
- Continuous
- Comprehensive
- Coordinated
- Compassionate
- Culturally-Competent

Learn more about the Medical Home Model here:

<https://www.pcpcc.org/about/medical-home>

### **About the SPAN Parent Advocacy Network:**

***Our Mission*** is to empower and support families and inform and involve professionals interested in the healthy development and education of children and youth. Our focus is on the whole child and family, including education, health and mental health, human services, child care and early childhood development, and child welfare/prevention.

***Our Foremost Commitment*** is to children and families with the greatest need due to disability or special health/mental health needs; poverty; discrimination based on race, gender or gender identification, language, immigrant or homeless status; involvement in the foster care, child welfare, or juvenile justice systems; geographic location; or other special circumstances.

***Our Vision*** is that all families will have the resources and support they need to ensure that their children become fully participating and contributing members of our communities and society.

***Our Motto*** is *Empowered Parents: Educated, Engaged, Effective!*

We hope that we can help you along your journey.

## Did you know?

- ❖ 4 million children have mental health issues
- ❖ 1 in 5 children ages 9 and up have an identified mental illness
- ❖ 50% of lifetime cases begin by age 14
- ❖ Only 20% of children are able to access needed mental health care
- ❖ 50% of kids with mental illness drop out of school before graduating
- ❖ 70% of children in juvenile justice system have mental health issues
- ❖ Research shows that early identification and treatment result in best outcomes<sup>1</sup>



*Photo population-based-intervention.wikispaces.com*

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<sup>1</sup> <https://nami.org/mhstats>

## What Parents and Professionals Need to Know about Mental Health

### *Access to care*

Mental health is just as important as physical health. The Affordable Care Act strengthened access to mental health services. One of the ten Essential Health Benefits is coverage for “mental health and substance use disorder services, including behavioral health treatment.”

Increased access to behavioral health treatment may also make it easier to get coverage for autism. Although NJ has an “autism and other developmental disabilities” mandate, it only applies to the 25% of health insurance plans that are subject to state regulations. Federal mental health parity means that mental health treatment must be equal to that for physical health. (Note: NJ has a mental health parity law that is even stronger than the federal law.)

### *Avoiding Stigma*

**Child & Adolescent Action Center**



In dealing with mental health, families must

try to avoid the stigma associated with mental illness. The National Alliance on Mental Illness (NAMI) ([www.nami.org](http://www.nami.org)) compares it to any other biologically-based illness, except the organ affected just happens to be the brain, and the symptoms manifest as behavior. Just as no one would blame someone with diabetes who needed insulin, the same should be true for those who need treatment for mental illness. Although the recent instances of school violence have opened the dialogue on mental illness, research indicates that people with mental health issues are more likely to be victims, rather than perpetrators, of violence.

NAMI has programs that help parents and schools work together (see section on Schools and Mental Health.)

## When to Get Help

Sometimes families can be confused or even unnecessarily embarrassed about getting help. It may be difficult for parents to know what their child is thinking (e.g., sad, angry, lost interest, etc.) Sometimes families just have indications that something is wrong by how the child is acting.

Clues can be:

- ✓ Frequent temper tantrums
- ✓ Crying more than usual
- ✓ Not doing things they enjoy
- ✓ Waking up at night
- ✓ Needing a routine or doing the same things over and over
- ✓ Overeating or extreme dieting
- ✓ Not being able to sit still or pay attention
- ✓ Doing poorly in school
- ✓ Drinking, smoking, using drugs
- ✓ Not dealing well with loss (such as death in the family)
- ✓ Trauma (natural disaster, abuse, accident etc.)
- ✓ Any behavior that is harmful to themselves or others

If the thoughts, feelings, or behaviors are frequent, intense, of long duration, or are having a negative impact on anyone . . . it's time to seek help.

Families should know that getting help is a sign of strength, not weakness. Parents are brave in recognizing that there is a problem and trying to fix it. Families also need to realize that they are not alone.



Photo [www.unitedwayaustin.org](http://www.unitedwayaustin.org)

## What to Expect

What to expect may be different depending on how the child gets involved with the mental health system. Usually, parents are able to find a professional when they have concerns. Some children, however, may have a crisis and end up in the hospital. For more information on mobile response for a crisis, see the section on the Children's System of Care. Families can find mental health professionals using the organizations listed in this guide such as the Children's System of Care, National Alliance on Mental Illness, and Federation of Families for Children's Mental Health; through other parents; or by asking their pediatrician or family practitioner. Sometimes there is a waiting list to see a specialist. Families can ask to be called if there are any cancellations and can call weekly for updates. By contacting the Mental Health Association ([www.mhanj.org](http://www.mhanj.org)), parents may be able to get information on faster access.

Usually, the mental health provider will do an assessment of the child, including family history. They may use tests to screen for certain conditions. If the assessment shows the possibility of a disorder, the child may need a more detailed evaluation to reach a diagnosis.



Photo [www.childrensdefense.org](http://www.childrensdefense.org)

NAMI has a family guide on how to include mental health with care from your child's primary care doctor at <https://www.nami.org/Advocacy/Policy-Priorities/Improving-Health/Physical-Mental-Health-Integration>



Photo <http://forourkids1st.blogspot.com>

## The Diagnosis

Sometimes “not knowing” is worse than actually having a name for the condition. Once parents know what’s happening, they may not feel so helpless or hopeless. Exceptional Parent magazine has an annual resource guide that lists all of the national organizations for specific conditions at [www.epmagazine.com/archive](http://www.epmagazine.com/archive)

(click on “preview”, then “archived”).

The Parent Center Hub has a section on mental health at [www.parentcenterhub.org/repository/emotionaldisturbance/](http://www.parentcenterhub.org/repository/emotionaldisturbance/) (in Spanish at [www.parentcenterhub.org/repository/emocional/.](http://www.parentcenterhub.org/repository/emocional/)) The Maternal/Child Health Knowledge Path for Families has information on both healthy social/emotional development at [www.mchlibrary.org/professionals/mental-healthy.php](http://www.mchlibrary.org/professionals/mental-healthy.php) as well as mental health conditions at [www.mchlibrary.org/professionals/mental-conditions.php](http://www.mchlibrary.org/professionals/mental-conditions.php)

The child may start having questions and ask about his/her condition. Children may ask, “Why I am I different,” or “Why is it so much harder for me to do things?” Sometimes children may just want to know what something is called. Other times they may want their parents to explain what it means. Families can start with children’s books that explain certain conditions. Children need to understand that they are not “better or worse”, simply different. They should also explain that a diagnosis doesn’t define their life or their future. Physical or visible disabilities can be easier to explain and to understand for children (and even adults). An excellent publication is “The Storm in My Brain” at

<https://secure2.convio.net/dabsa/pdfs/storm.pdf>



Photo [www.dbsalliance.org](http://www.dbsalliance.org)

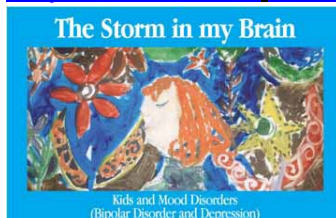


Photo [www.theguardian.com](http://www.theguardian.com)

For older youth, there is a good publication “Accepting My Disability” which discusses positive outlook, accommodations, self-advocacy etc. [www.going-to-college.org/myplace/disability.html](http://www.going-to-college.org/myplace/disability.html)



## Medication

Medication use is a personal decision. Families need to realize, however, that mental illness is “biologically based,” although there are physical, social, and environmental factors that can play a role in their development. Families may also be concerned about the “black box warnings” on certain medications for children. This warning is often warranted, but has predictably lowered the use of certain prescriptions. However, it is important to recognize that untreated depression is the highest risk factor for suicide. There are some excellent guides on medication use which should help parents, which also address this issue of balance.



NAMI’s “Family Guide on Adolescent Depression” includes information about treatment, medication, and the “black box warning.” It includes good questions to ask providers such as:

- What are the benefits vs. the risks of the medication?
- What are the side effects of the medication?
- How can the child be involved in the decision-making process?

The family guide is found at [www.nami.org/getattachment/Press-Media/Press-Releases/2010/NAMI-Releases-Family-Guide-on-Adolescent-Depressio/FamilyGuide2010.pdf](http://www.nami.org/getattachment/Press-Media/Press-Releases/2010/NAMI-Releases-Family-Guide-on-Adolescent-Depressio/FamilyGuide2010.pdf)

Parents Med Guide is a series of guides which are endorsed by the American Psychiatric Association and American Academy of Child & Adolescent Psychiatry:

- The ADHD Parent's Medication Guide is available in English and Spanish.
- Parent's Medication Guide for Bipolar Disorder is only available in English.
- The Use of Medication in Treating Childhood and Adolescent Depression: Information for Patients and Families is only available in English.

All of the guides can be found at [www.parentsmedguide.org/](http://www.parentsmedguide.org/).



NYU Medical Center has a listing of different types of medications for children's mental illness and their uses in English at [www.aboutourkids.org/articles/guide\\_psychiatric\\_medications\\_children\\_adolescents](http://www.aboutourkids.org/articles/guide_psychiatric_medications_children_adolescents) or in Spanish at [www.aboutourkids.org/espanol/trastornos\\_y\\_tratamientos/guia\\_de\\_medicamentos\\_psiquiaticos\\_para\\_ninos\\_y\\_adolescentes](http://www.aboutourkids.org/espanol/trastornos_y_tratamientos/guia_de_medicamentos_psiquiaticos_para_ninos_y_adolescentes).

## Supports and Services

The Substance Abuse and Mental Health Services Administration (SAMHSA) emphasizes a Wellness/Recovery Model. Prevention, as well as getting better, are the key ideas. This idea of wellness is based on “evidence-based practices” (proven to work.) The key recovery concepts are hope, education, personal responsibility, support and self-advocacy. For more information, see [www.samhsa.gov/recovery](http://www.samhsa.gov/recovery). SAMHSA also lists treatments by condition at [www.samhsa.gov/treatment/mental-disorders](http://www.samhsa.gov/treatment/mental-disorders) as well as a searchable treatment locator at <https://findtreatment.samhsa.gov/>

NAMI has a family guide on choosing the right treatment at [www.aacap.org/App\\_Themes/AACAP/docs/member\\_resources/toolbox\\_for\\_clinical\\_practice\\_and\\_outcomes/sources/NAMI\\_Handbook.pdf](http://www.aacap.org/App_Themes/AACAP/docs/member_resources/toolbox_for_clinical_practice_and_outcomes/sources/NAMI_Handbook.pdf). There are also classes for families dealing with mental illness at [www.nami.org/Support-Education/Mental-Health-Education/NAMI-Basics](http://www.nami.org/Support-Education/Mental-Health-Education/NAMI-Basics); for Spanish classes, contact Martha Silva at (888) 803-3413 or [naminjenespanol@msn.com](mailto:naminjenespanol@msn.com). NAMI has additional national resources from their Child & Adolescent Action Center at [www.nami.org/Your-Journey/Kids-Teens-and-Young-Adults](http://www.nami.org/Your-Journey/Kids-Teens-and-Young-Adults)

### *A special note on Natural Disasters*

Natural disasters have an impact on children’s mental health. An excellent resource is “Coping with Crisis: Helping Children with Special Needs” at [http://www.nasponline.org/resources/crisis\\_safety/specpop\\_general.aspx](http://www.nasponline.org/resources/crisis_safety/specpop_general.aspx).

Sometimes parents just want to talk to other families who have “been there.” New Jersey’s Family Support Organizations (FSOs) are a good place to start and can be found at <http://njfamilyalliance.org/>. Parent-to-Parent matches trained volunteer families to other families with the same condition and can be found at (800) 654-SPAN x 121. A list of support groups can be found at [www.njgroups.org/](http://www.njgroups.org/).

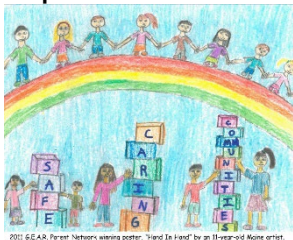


Photo [www.thriveinitiative.org](http://www.thriveinitiative.org)

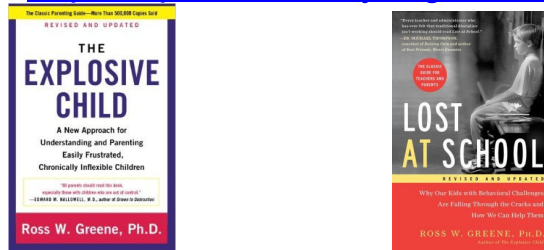
## Schools and Mental Health

Collaboration and education on mental health in the school setting is critical. Children spend many hours in school. Schools have a responsibility to identify children who may have emotional, behavioral, and/or mental health challenges. When there are concerns, the child may go through the Intervention and Referral Services (I&RS) Team. The team may decide that the child just needs extra supports in school and then look at NJ Multi-Tiered Systems of Support, which requires the school to provide *evidence-based* interventions and then determine whether those interventions had the desired effect. In most cases, this should be done before a child is evaluated for eligibility for special education. (However, if a child already has a diagnosed mental health condition, or if the parent or school staff suspect that the child has an emotional or other disability, the child should be referred to the special education team for a meeting with the parent to decide whether or not a special education or Section 504 evaluation will be conducted). For more information on this process, see [www.nj.gov/education/njtss/brief.pdf](http://www.nj.gov/education/njtss/brief.pdf). Some children with mental health issues have IEPs (Individualized Education Program) while others may be served under a Section 504 plan. For more information, see [www.understood.org/en/articles/at-a-glance-which-laws-do-what](http://www.understood.org/en/articles/at-a-glance-which-laws-do-what). You can also see a comparison of special education IEPs vs. Section 504 at <https://spanadvocacy.org/download/guide-to-services-for-students-with-disabilities-idea-section-504-of-the-vocational-rehabilitation-act/>. A fact sheet explaining the Section 504 and Americans with Disabilities Act protections in public school can be found at <https://spanadvocacy.org/download/section-504-and-the-americans-with-disabilities-act-ada-in-schools/?wpdmdl=52185&ind=1559666309282>. An important piece for success at school is the use of Positive Behavioral Interventions and Supports. Challenging behaviors are often the result of the child trying to communicate the best he/she can. Family information on positive supports can be found at <https://www.pbis.org/topics/family>



Photo [www.pbis.org](http://www.pbis.org)

A child may need to have a Functional Behavioral Assessment done at school to understand why they are acting in a certain way and what supports can be put in place to prevent or ameliorate those behaviors. Schools can't change the child's educational placement without holding a meeting, unless it's an emergency situation. In addition, if the child breaks the conduct code/school rules and the school wants to remove the child, they must do a Manifestation Determination to decide if the behavior was caused by the disability. You can find SPAN's guide to Manifestation Determination, Functional Behavioral Assessment, and Positive Behavior Supports at <https://spanadvocacy.org/downloads/behavior/>



Authors Ross Greene, PhD and J Stuart Ablon, PhD strongly believe that “children will do well if they can.” This philosophy takes a non-blameful approach based on decades of research which indicates that many challenging behaviors are actually the result of skill deficits, not on manipulation or a lack of motivation, as many adults believe. This explains why traditional forms of intervention, such as rewards and punishments, often do not work for children who are the most challenging. The Collaborative Problem-Solving model (or Collaborative Proactive Solutions as the model may also be referred to), articulated in their books:

1. Allows adults to pursue expectations
2. Reduces challenging behaviors
3. Teaches lagging skills
4. Improves the relationship between the child and adult
5. Solves problems

The model includes a step-by-step approach on how to help children and adults work together toward realistic and mutually satisfactory solutions underlying difficult behavior. The model can be used with children of all ages and works in home or school settings. For more information, visit [www.livesinthebalance.org](http://www.livesinthebalance.org) or [www.thinkkids.org](http://www.thinkkids.org)



NAMI NJ's Educating the Educators (ETE) and NAMI National's Parents & Teachers as Allies (PT&A) programs are designed to help school staff understand mental health challenges in children.

Two other programs are designed for student audiences: NAMI NJ's Every Mind Matters (EMM) for middle or high school students and NAMI National's Ending the Silence (ETS) high school students.

ETE can offer NJ professional development credits and EMM is aligned with the NJ Core Curriculum Content Standards. For more information on NAMI NJ's school programs: [www.naminj.org/programs/school-programs/](http://www.naminj.org/programs/school-programs/). For general information on mental health and schools visit NAMI National's website: [www.nami.org/Advocacy/Policy-Priorities/Improving-Health/Mental-Health-in-Schools](http://www.nami.org/Advocacy/Policy-Priorities/Improving-Health/Mental-Health-in-Schools)

The Parent Center Hub has information on mental health and schools at [www.parentcenterhub.org/?s=mental+health](http://www.parentcenterhub.org/?s=mental+health). In each state there is a Parent Training and Information Center (PTI). Parent Centers help families with early intervention and school issues at no cost. SPAN Parent Advocacy Network is the PTI for New Jersey. SPAN is also the [NJ State Organization of the National Federation of Families for Children's Mental Health](#). Our warmline is (800) 654-SPAN.

## The Children's System of Care in New Jersey

New Jersey was the first state to implement a statewide children's system of care for child behavior health. The NJ Children's System of Care (CSOC) was phased into various counties beginning in 2001 with completed statewide implementation in 2006. PerformCare is currently the "contracted systems administrator" (CSA) for the System of Care and serves as a single, central point of entry.

The statewide hotline number is **1-877-652-7624**. Calls to the hotline are "triaged," which means that urgent calls are handled first.

The structure of NJ's system of care includes:

- ✓ **Mobile Response & Stabilization Services (MRSS)**

*Used for crisis and stabilization. Mobile response will go to the family's home, school, or other setting to de-escalate the situation and help the family decide next steps. Please note: this is a difference service than Mobile Outreach (see Glossary for description of Mobile Outreach).*

- ✓ **Unified Case Management (UCM)**

*Provides two levels of care: 1) "care management" for children with more intensive needs and 2) "youth case management" (YCM) for children with less intensive needs. Services are coordinated by county Care Management Organizations (CMOs).*

- ✓ **Family Support Organizations (FSO)**

*The FSO's provide peer support for parents. Staffed by family leaders, parents can get additional support and information by calling or attending workshops. In New Jersey, the Family Support Organizations in each county have information and support for parents at <http://njfamilyalliance.org/> or for Spanish just click on "translate" button.*



Photo <http://njfamilyalliance.org/>

**An important note:** As of January 2013, PerformCare also includes children with developmental disabilities (DD) and substance use disorders. This is especially important for families who may be dealing with both DD and mental illness. There is now an online application for DD at [www.performcarenj.org/families/disability/determination-eligibility.aspx](http://www.performcarenj.org/families/disability/determination-eligibility.aspx).

The CSOC is intended to be family-centered and family-driven. All meetings and services should take place at a time convenient for the family and child.

The CSOC is voluntary and there are no fees for services, although they may coordinate with private insurance companies.

There is a PerformCare Parent Guide available at [www.performcarenj.org/pdf/provider/youth-family-guide-eng.pdf](http://www.performcarenj.org/pdf/provider/youth-family-guide-eng.pdf) or Spanish [www.performcarenj.org/pdf/provider/youth-family-guide-span.pdf](http://www.performcarenj.org/pdf/provider/youth-family-guide-span.pdf). For more information on the Children's System of Care go to [www.nj.gov/dcf/about/divisions/dcsc/](http://www.nj.gov/dcf/about/divisions/dcsc/). Additional information for PerformCare can be found at [www.performcarenj.org/](http://www.performcarenj.org/).





## Where to Find Help In Your Community

Besides Family Support Organizations under the Children's System of Care, there are several other organizations nationally and in NJ that support families who have children with challenging behaviors.



Photo [www.coordinatedfamilycare.org](http://www.coordinatedfamilycare.org)

*National Federation of Families (formerly National Federation of Families for Children's Mental Health)*

### **NATIONAL FEDERATION OF FAMILIES**

*Bringing Lived Experience to Family Support*



The National Federation of Families is a national family-run organization linking more than 120 chapters and state organizations focused on the issues of children and youth with emotional, behavioral, or mental health needs and their families.” The Federation affiliates can be found at [www.ffcmh.org/our-affiliates](http://www.ffcmh.org/our-affiliates). SPAN is the NJ State Organization of the Federation. As the federally designated Parent Training and Information Center, SPAN can help families of children with mental health concerns deal with early intervention, school, and transition to adult life issues. SPAN is also the home of NJ Family Voices/Family-to-Family Health Information Center which can help families get information on diagnosis, insurance coverage, and other health-related issues for children with special needs, including mental health/emotional needs. Lastly, SPAN houses NJ Parent-to-Parent which matches trained volunteer parents to families of children with the same diagnosis to provide emotional support.

*National Alliance on Mental Illness*



NAMI has workshops for families and [www.nami.org/Support-Education/Mental-Health-Education/NAMI-Basics](http://www.nami.org/Support-Education/Mental-Health-Education/NAMI-Basics) or for Spanish contact Martha Silva at (888) 803-3413 or [naminjenespanol@msn.com](mailto:naminjenespanol@msn.com). NAMI has additional resources from their Child & Adolescent Action Center at [www.nami.org/getattachment/Press-Media/Press-Releases/2010/NAMI-Releases-Family-Guide-on-Adolescent-Depressio/FamilyGuide2010.pdf](http://www.nami.org/getattachment/Press-Media/Press-Releases/2010/NAMI-Releases-Family-Guide-on-Adolescent-Depressio/FamilyGuide2010.pdf)

NAMI has a family guide on how the primary care provider (e.g., pediatrician) can address mental health at [www.nami.org/Advocacy/Policy-Priorities/Improving-Health/Physical-Mental-Health-Integration](http://www.nami.org/Advocacy/Policy-Priorities/Improving-Health/Physical-Mental-Health-Integration). Families can find their NAMI for their county at [www.naminj.org/support/affiliates/](http://www.naminj.org/support/affiliates/).

*Mom2Mom*

Mom2Mom is a 24/7 peer support helpline for parents of children (of any age) with any kind of special need 877-914-6662 (877-914-Mom2). The helpline is staffed by mothers of children with special needs who have been trained with the support of mental health clinicians. Mom2Mom is based at Rutgers University Behavioral Health Care <http://www.mom2mom.us.com/>.



## Advocacy/Self-Advocacy Issues

There are some issues regarding mental health that may affect children, youth, and young adults. These can include minor consent, making medical decisions, parent's rights, restraints, waiting in emergency rooms, and dual diagnosis of mental illness and developmental disability. For self-advocates, the Centers for Independent Living help with life skills to maximize independence and are found at [www.njsilc.org](http://www.njsilc.org).

### ❖ Minor Consent

In NJ, at age 14 children have the right to have input into their treatment, including hospitalization and medication. The PerformCare family guide states, "Where a youth at least 14 years of age or older is receiving services provided through CSOC, written authorization by the youth is required to release information to a parent/legal guardian or third party."

### ❖ Alternatives to Guardianship

Most young adults with mental health issues do not need guardianship, as they are competent decision-makers. Some children and teens will have ongoing challenges after age 18. Supported Decision Making is one alternative to guardianship. Another option may be a durable power of attorney, which is revocable at any time by the young adult, but may be useful during crisis when they need support in decision-making and allows providers to communicate with the person holding the durable power of attorney. You may wish to consult an attorney for information on the various options. Check out this fact sheet from the NJ Departments of Children and Families, Education, and Human Services at [www.nj.gov/education/specialed/transition/GuardianshipBrochure.pdf](http://www.nj.gov/education/specialed/transition/GuardianshipBrochure.pdf). You can also find information in SPAN's Family Guide to Transition Services at <https://spanadvocacy.org/download/family-guide-to-transition-services/> and the National Resource Center for Supported Decision-Making at [www.supporteddecisionmaking.org/](http://www.supporteddecisionmaking.org/).

### ❖ Parental Rights

Families do NOT have to give up their custodial rights in order for their child to get treatment. If families give up their parental rights, the child becomes a ward of the state and the family has no say in what happens or where they are placed.

### ❖ Restraints

Parents do NOT have to sign any documents, including IEPs, which allow the use of aversive interventions, restraints, or seclusion, in order for their child to get placement or services. The inappropriate use of restraints, including chemical restraints, is experienced as trauma. Best practices are the use of Positive Behavioral Interventions and Supports (see <http://www.pbis.org/>.) You can access “What Parents Should Know About the Use of Restraint and Seclusion” at <https://spanadvocacy.org/download/what-parents-should-know-about-the-use-of-restraints-seclusion/>

### ❖ Shortage of “beds”

Sometimes even in a crisis, there isn't an immediate place available for hospitalization. This means that some children end up waiting in the hospital emergency room. There is a limit of 24 hours wait time for children. Some hospitals have also now developed pediatric emergency rooms.

### ❖ Dual Diagnosis

At times it may be difficult to determine if the behavior of a child with a dual diagnosis of developmental and emotional disability is due to the developmental disability. The key factor in deciding if the behavior appears to be a mental health crisis. It may be even harder for children with a dual diagnosis to find a hospital bed. However, with the move of children with developmental disabilities to the Department of Children and Families, which also serves children with mental health issues, this should become easier over time.

If families are having problems with advocacy issues, they can contact their Family Support Organization at <http://njfamilyalliance.org/>, the National Alliance on Mental Illness at [www.naminj.org/support/affiliates/](http://www.naminj.org/support/affiliates/), or SPAN at (800) 654-SPAN.



Photo [www.galleryhip.com](http://www.galleryhip.com)

## Other good resources for families:

### Young Children

- ❖ Center on the Social and Emotional Foundations for Early Learning- Family Tools  
[www.edutopia.org/social-emotional-learning-parent-resources](http://www.edutopia.org/social-emotional-learning-parent-resources)
- ❖ First Steps: A guide for Parents of Young Children with Developmental Chapters 1-4 (diagnosis based on age, parent feelings, definition of developmental disabilities, individual/family adjustment) [https://fddc.org/wp-content/uploads/2020/08/First Steps Guide English.pdf](https://fddc.org/wp-content/uploads/2020/08/First_Steps_Guide_English.pdf)

### All ages

- ❖ Bright Futures in Practice (what to expect by age)  
[www.brightfutures.org/mentalhealth/pdf/tools.html](http://www.brightfutures.org/mentalhealth/pdf/tools.html)
- ❖ Emotional, Behavioral, and Mental Health Challenges in Children and Adolescents- Maternal/Child Health Knowledge Path - U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal/Child Health Bureau  
[www.mchlibrary.org/professionals/mental-conditions.php](http://www.mchlibrary.org/professionals/mental-conditions.php)
- ❖ Family Guide to Systems of Care for Children with Mental Health Needs  
<https://spanadvocacy.org/download/nj-federation-of-families-for-childrens-mental-health/?wpdmdl=53120&ind=1571333689107>

Parents of children with disabilities need to realize when their child, or other family members, need some support, and reach out to get the help they need!



[www.aamentalhealth.org](http://www.aamentalhealth.org)

## Glossary of Terms

**Advocacy:** Speaking on behalf of yourself or someone else so they get what they need.

**Aversives, Restraint, Seclusion:** Physical punishment, putting the person in restraints, or isolating the person from others

**Care Management Organizations (CMOs):** County-based, nonprofit organizations responsible for face-to-face care management and comprehensive service planning for youth and their families with intense and/or complex needs. If a youth is receiving services from the *Children's System of Care* that include care management, it would not be appropriate to receive additional care management through a CMO.

**Children's System of Care:** Serves children with mental health and/or developmental challenges.

**Collaborative Problem-Solving:** Working together with the child and/or professionals to resolve an issue.

**Diagnosis:** The name of the condition.

**Dual Diagnosis:** Having more than one condition, often a Developmental Disability along with a mental health disability.

**Evidence-Based Interventions:** Actions to improve a situation than have been proven to work.

**Family Support Organizations:** Under the Children's System of Care, family-led agencies providing support and information.

**Functional Behavioral Assessment:** An assessment to determine why the child is acting in a certain way, done at school.

**Information & Referral Services:** A coordinated system for planning and delivering intervention and referral services to assist students who are experiencing difficulties with needs in the areas of: Learning, Behavior and/or Health

**Individualized Education Program/504 Plan:** Plans to address the needs of students with disabilities, used in school.

**Level of Care:** The amount and types of services available under the *Children's System of Care* based on the child's needs (see [www.performcarenj.org/pdf/provider/clinicalcriteria/cmo-moderate.pdf](http://www.performcarenj.org/pdf/provider/clinicalcriteria/cmo-moderate.pdf))

**Manifestation Determination:** A meeting to decide if the behavior was caused by the disability, done before the child with a disability can be removed from school.

**Minor Consent:** The age when the child has input into decisions made about treatment.

**Mobile Response & Stabilization Services (MRSS):** Provides 24/7 de-escalation for children experiencing escalating behaviors or crisis.

**Mobile Outreach:** Mental Health professional from the designated county screening center who can be dispatched into the community to help evaluate a child (or adult) for suicidal ideation.

**Multi-Systemic Therapy (MST) and Family Functional Therapy (FFT):** Six-month, intensive family therapy models that are often offered to youth involved with, or at risk of, involvement with the juvenile justice system.

**PerformCare:** The name of the agency under contract with the Children's System of Care to serve as the central point of entry.

**Positive Behavioral Interventions & Supports:** Using positive ways to change behavior rather than punishment.

**Recovery/Wellness:** The model that people with mental illness can get better and that prevention works.

**Stigma:** Negative, untrue, and unfair beliefs about a condition or disability.

**Self Advocacy:** Speaking up for yourself, having a voice in decisions that impact your life.

**Youth Case Management:** A lower level of support under the *Children's System of Care*



## How to Find Us:

SPAN Parent Advocacy Network

35 Halsey St., 4<sup>th</sup> Fl., Newark, NJ 07102

(800)654-SPAN

[www.spanadvocacy.org](http://www.spanadvocacy.org)

email <http://www.spanadvocacy.org/content/contact-us>

FB <https://www.facebook.com/parentadvocacynetwork>

Twitter <https://twitter.com/@spanvoice>



**For more information on health advocacy across the lifespan, including alternatives to guardianship and self-advocacy, see SPAN's manual "A GPS for Families of and Individuals with Disabilities: Health Advocacy Guide" at <https://spanadvocacy.org/published/>**

This guide was adapted from "A Family Guide to Children's Mental Health Services and Supports" Department of Children & Families, FL.