Children's Mental Health: A National Family Guide

SPAN
Parent Advocacy Network

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 the important decisions needed to ensure that your child with mental health challenges 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. 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
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[1]

Photo population-based-intervention.wikispaces.com

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 some states like NJ have an "autism and other developmental disabilities" mandate, it only applies to 25% of plans which are subject to state regulations. Federal mental health parity means that mental health treatment must be equal to that for physical health.

Avoiding Stigma

Photo www.nami.org

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) likens 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 displays of school violence have opened the dialogue on mental illness, research indicates that people with mental health issues are more like 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 on page 14)

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, 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, 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

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.

When families need to find help they can find mental health professionals using the organizations listed in this guide such as the National Alliance on Mental Illness, 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. Mental Health America (www.mentalhealthamerica.net/) may give parents information on faster access.

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

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 the "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 the national organizations for specific conditions at http://digital.turn-page.com/t/99327 (click on preview, then archived.) The Parent Center Hub has a section on mental health at http://www.parentcenterhub.org/repository/emotionaldisturbance/ or Spanish http://www.parentcenterhub.org/repository/emocional/. The Maternal/Child Health Knowledge Path for Families has information on both healthy social/emotional development at http://www.mchlibrary.org/families/frb_Mental_Healthy.html as well as mental health conditions at http://www.mchlibrary.org/families/frb_Mental_Conditions.html.

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

http://www.dbsalliance.org/pdfs/storm.pdf.

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

Photo www.theguardian.com

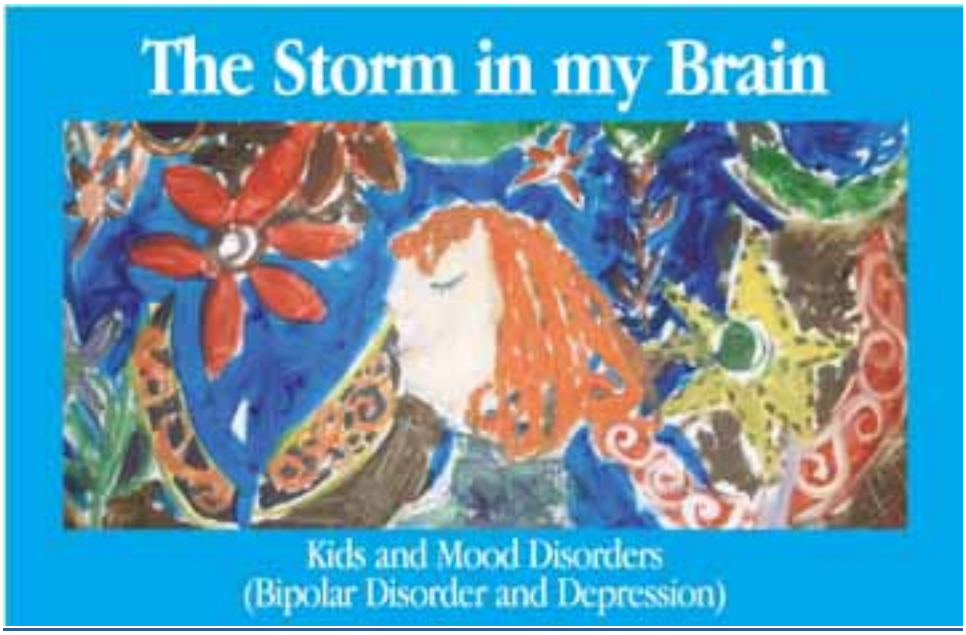


Photo www.dbsalliance.org

Medication

Medication use is a personal decision. Families need to realize, however, that mental illness is "biologically based." Families may also be concerned about the "black box warnings" on certain medications for children. The warning, although warranted, has predictably lowered the amount of certain prescriptions; however, there must be recognition 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
http://www.nami.org/Content/ContentGroups/CAAC/FamilyGuidePRINT.pdf

ParentsMedGuide.org
helping parents help their kids

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/.

NYU Langone MEDICAL CENTER

NYU Medical Center has a listing of different types of medications for children's mental illness and their uses at http://www.aboutourkids.org/articles/guide_psychiatric_medications_children_adolescents or Spanish http://www.aboutourkids.org/espanol/trastornos_y_tratamientos/guia_de_medicamentos_psiquiatricos_para_ninos_y_adolescentes.

Supports and Services

SAMHSA (Substance Abuse and Mental Health Services Administration) 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 http://www.samhsa.gov/recovery. SAMHSA also lists treatments by condition at http://www.samhsa.gov/treatment/mental-disorders as well as a searchable treatment locator at http://findtreatment.samhsa.gov/locator/link-focChild.

NAMI has a family guide on choosing the right treatment at http://www.nami.org/Content/ContentGroups/CAAC/ChoosingRightTreatment.pdf. There are also classes for families dealing with mental illness at http://www.nami.org/Local-NAMI/Programs?classkey=e4bf6c93-2a0e-490f-982b-c1352ec1298e. Nationally NAMI has additional resources from their Child & Adolescent Action Center at www.nami.org/Template.cfm?Section=For_Parents,_Caregivers,_and_Youth&Template=/ContentManagement/ContentDisplay.cfm&ContentID=37809 or Spanish www.nami.org/Template.cfm?Section=Child_and_Adolescent_Action_Center&template=/ContentManagement/ContentDisplay.cfm&ContentID=21090.

A special note on Natural Disasters

Natural disasters have an impact on children's mental health. We have a guide for families who were affected by hurricane Sandy which has resources for families at http://www.spanadvocacy.org/sites/startingpointstemplate.drupalgardens.com/files/files/Mental_Health_Information_and_Resources_for_Families_Impacted_by_Hurricane_Sandy_with_logos.pdf. There is also "Coping with Crisis: Helping Children with Special Needs" at http://www.nasponline.org/resources/crisis_safety/specpop_general.aspx.

Sometimes parents just want to talk to other families who have “been there.” Parent-to-Parent matches trained volunteer families to other families with the same condition and can be found at http://www.p2pusa.org/p2pusa/SitePages/p2p-support.aspx. Support groups can be found through local affiliates of Mental Health America at http://www.mentalhealthamerica.net/find-affiliate.

2011 G.E.A.R. Parent Network winning poster, “Hand In Hand” by an 11-year-old Maine artist.

Photo www.thriveinitiative.org

Schools and Mental Health

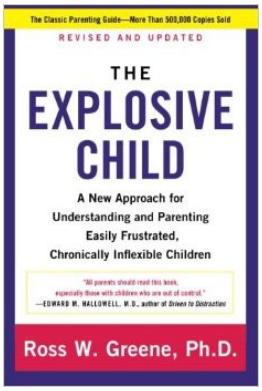
Collaboration and education on mental health in the school setting is critical. Children spend many hours in the school environment. Schools have a responsibility to identify children who may have emotional, behavioral, and/or mental health challenges. When there are concerns, the child may go through 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 Response to Invention (RTI), 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.spannj.org/keychanges/education_materials09/Early_Intervening_Services.pdf. Some children with mental health issues have IEPs (Individualized Education Program) while others may just need accommodations under a 504 plan. For more information, see the "Parent Guide to Services for Students with Disabilities under IDEA, ADA, & 504" at http://www.spanadvocacy.org/sites/g/files/g524681/f/documents/IDEA%20504%20ADA%20National%20Parent%20Guide.pdf.

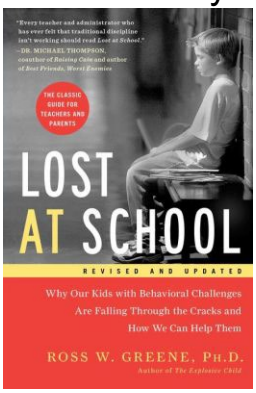
An important piece for success at school is the use of Positive Behavioral Interventions and Supports. Behavior is the result of the child trying to communicate the best he/she can. Family information on positive supports is found at http://www.pbis.org/family.

Photo www.pbis.org

Sometimes children need to have a Functional Behavioral Assessment done at school to decide why the child is acting in a certain way and what supports can be put in place. Also, schools can't change the child's

placement without holding a meeting, unless it's an emergency situation. In addition, if the child does something or even breaks the conduct code and the school wants to remove the child, they must do a Manifestation Determination to decide if the behavior was caused by the disability.





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 the most challenging children. 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 information, visit www.livesinthebalance.org or www.thinkkids.org

Lives IN THE Balance
Changing the conversation about and with behaviorally challenging kids
Think:Kids
RETHINKING CHALLENGING KIDS

NAMI's Provider Education as well as 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.

Provider Education may be able to offer professional development credits and EMM is aligned with the NJ Core Curriculum Content Standards. For more information on NAMI school programs: https://www.nami.org/Find-Support/NAMI-Programs/NAMI-Provider-Education. For general information on mental health and schools visit NAMI National's website: www.nami.org/Template.cfm?Section=Schools_and_Education&Template=/TaggedPage/TaggedPageDisplay.cfm&TPLID=74&ContentID=37844.

The Parent Center Hub has information on mental health and schools at www.parentcenterhub.org/?s=mental+health. In each state there is a Parent Training and Information Center (PTI). PTIs help families with early intervention and school issues at no cost. For NJ, the Statewide Parent Advocacy Network is the PTI. SPAN is also a chapter of the National Federation of Families for Children's Mental Health. Our warmline is (800)654-SPAN. Find the parent center in your state at www.parentcenterhub.org.

State Agencies on Children's Mental Health

Many states have a Department of Children and Families which can offer assistance. Some states have a "Children's System of Care" which covers behavioral health. There may also be "mobile response" available for crisis intervention which means they would go to where the child is, including home, to try and deescalate the crisis and stabilize the situation.

By way of illustration, NJ was the first state to implement a statewide children's system of care for child behavior health.

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.

PerformCARE Department of Children and Families
www.performcarenj.org/

Where to Find Help

In Your Community

Photo www.coordinatedfamilycare.org

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

Federation of Families for Children's Mental Health

NATIONAL FEDERATION OF FAMILIES
For Children's Mental Health
The National Family Voice for Children's Mental Health

FFCMH 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 FFCMH chapters can be found at http://www.ffcmh.org/chapters. The New Jersey Alliance of Family Support Organizations is the FFCMH's State Organization; SPAN is a member of the Alliance and serves on its Board. The Statewide Parent Advocacy Network is also a chapter of the FFCMH. As the federally designated Parent Training and Information Center, SPAN can help families of children with mental health concerns deal with school issues. SPAN is also the home of Family Voices/Family-to-Family Health Information Center which can help families get information on diagnosis, insurance coverage, etc. 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 at http://www.nami.org/Local-NAMI/Programs?classkey=e4bf6c93-2a0e-490f-982b-c1352ec1298e
NAMI has additional resources from their Child & Adolescent Action Center at www.nami.org/Template.cfm?Section=For_Parents,_Caregivers,_and_Youth&Template=/ContentManagement/ContentDisplay.cfm&ContentID=37809 or Spanish www.nami.org/Template.cfm?Section=Child_and_Adolescent_Action_Center&template=/ContentManagement/ContentDisplay.cfm&ContentID=21090. NAMI has a family guide on how the primary care provider (e.g., pediatrician) can address mental health at http://www.spanadvocacy.org/content/family-guide-integrating-mental-health-and-pediatric-primary-care. Families can find their local NAMI at http://www.nami.org/Find-Support/Family-Members-and-Caregivers.

Parent-to Parent

Parent-to-Parent is a national network offering support to families. Trained volunteer parents are matched with families of children with the same condition. These services are free to families. Parents can get one-to-one support from another parent "who's been there." Research shows that peer support is highly effective. Families can find their local Parent-to-Parent at http://www.p2pusa.org/p2pusa/SitePages/p2p-support.aspx

Advocacy/Self-Advocacy Issues

There are some issues regarding mental health that may affect children and also later as they become self-advocates. 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 http://www.ilru.org/projects/cil-net/cil-center-and-association-directory.

- ❖ Minor Consent

In some states, under the age of 18 children have the right to have input into their treatment, including hospitalization and medication. In NJ for example, 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 children with mental health issues do not need guardianship when they become adults as most of the time they are competent decision-makers or have recovered. However, some children will have ongoing challenges. A good option could 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. Consult your attorney for information on the various options.

- ❖ 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.

❖ 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 http://www.spanadvocacy.org/content/what-parents-should-know-about-use-restraint-and-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 is due to the developmental disability. The key factor in deciding is if it 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 recent 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 the Federation of Families for Children's Mental Health at http://www.ffcmh.org/chapters, the National Alliance on Mental Illness at www.naminj.org/support/affiliates/, or their Parent Training and Information Center at http://www.parentcenterhub.org/find-your-center/.

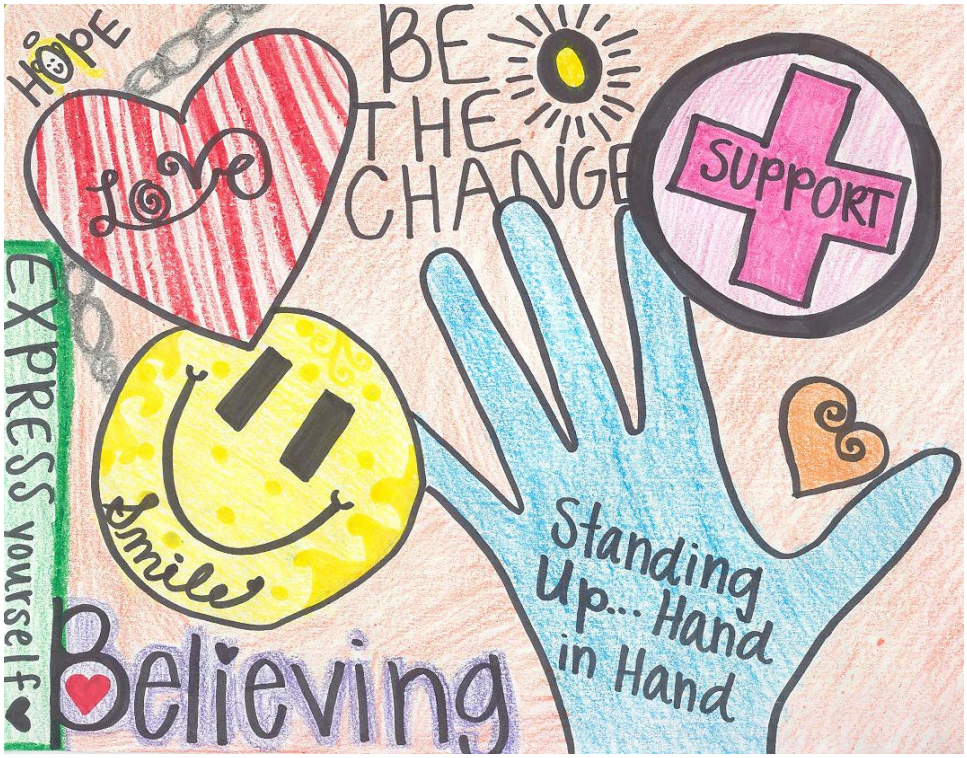


Photo www.galleryhip.com

Other good resources for families:

Young Children

- Center on the Social and Emotional Foundations for Early Learning-Family Tools
  http://csefel.vanderbilt.edu/resources/family.html

- 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)
  www.fddc.org/sites/default/files/file/publications/first_steps/FSSTEPSEngColor01-05.pdf or Spanish
  www.fddc.org/sites/default/files/file/publications/first_steps/FSSTEPSSpaColor01-05.pdf

All ages

- A Family Guide to Children's Mental Health Services and Supports - Florida Department of Children and Families www.dcf.state.fl.us/programs/samh/mentalhealth/docs/FamilyGuideBookDCF.pdf

- Bright Futures in Practice (what to expect by age) 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/KnowledgePaths/kp_Mental_Conditions.html

- Family Guide to Systems of Care for Children with Mental Health Needs http://store.samhsa.gov/product/Family-Guide-to-Systems-of-Care-for-Children-With-Mental-Health-Needs-bilingual-English-Spanish-/SMA05-4054

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

Glossary of Terms

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

Aversives, Restraints, Seclusion
Physical punishment, putting the person in restraints, or isolating the person from others

Collaborative Problem-Solving
Working together with the child to resolve an issue.

Diagnosis
The name of the condition.

Dual Diagnosis
Having more than one condition.

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

Functional Behavioral Assessment
A test to decide why the child is acting in a certain way, done at school.

Information & Referral Services
Extra support in school used before testing for special education.

Individualized Education Program/504 Plan
Student special education plans used in school.

Manifestation Determination
A hearing to decide if the behavior was caused by the disability, done before the child can be removed from school.

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

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

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, a disability, etc.

Self Advocacy
Speaking up for yourself and having control.

How to Find Us:

Statewide Parent Advocacy Network

35 Halsey St., 4th Fl., Newark, NJ 07102

(800)654-SPAN

Website www.spanadvocacy.org

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

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

Twitter https://twitter.com/@spanvoice

SPAN Statewide Parent Advocacy Network

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/download/a-gps-for-families-of-people-with-special-needs/

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