



DOERNBECHER
CHILDREN'S
Hospital

OCCYSHN

Oregon Center for Children and
Youth with Special Health Needs

A Compendium of Family Resources

Compiled for Presentation at the 2020 Child Psychiatry ECHO

Julie Magers, BA

OHSU Child & Adolescent Psychiatry Division (CAP)

Tamara Bakewell, MA

Oregon Center for Children and Youth with Special Health Needs (OCCYSHN)

Family-Led Peer Support Organizations

Why this resource: Peers with lived experience can support families during the “in between times.”

Current, vetted list of **family support organizations** available throughout Oregon.

The Oregon Family to Family Health Information Center is a clearinghouse for non-medical family resources and support.

This resource sheet is available in ECHO handouts.

Questions? Tamara Bakewell bakewell@ohsu.edu

OREGON FAMILY TO FAMILY HEALTH INFORMATION CENTER

The Oregon F2F HIC recommends the following parent-driven family support and information programs. The following organizations are staffed during regular business hours, serve families in every part of the state, and can respond to Spanish speaking callers immediately or within a short period. Services of these programs are offered to families for free.

Oregon Family to Family Health Information Center - 855-323-6744 (English) 503-931-8930 (Spanish)
www.oregonfamilytofamily.org Peer coaching and support to navigate health and mental health systems and other state, federal, and community services. Tip Sheets, toll-free phone line, website, and special-needs related publications.

FACT (Families and Communities Together) - www.factoregon.org -
Help with Special Education concerns, IEPs and person-centered planning. Translation support for numerous languages. Condition-specific parent m

All Born (In)/ Northwest Down Syndrome Association - <http://allborn.org>
503-238-0522 (English) 503-239-1509 or 971-570-0942 or 503-442
Family connections, advocacy skills, help with special education and support to have full lives. New parent kits, parent support, materials, family group

Autism Society of Oregon - www.autismsocietyoregon.org - 1-888-2
Autism-specific resources and information, "Take a Break" funding, support autism-related services and supports. Calendar of trainings and support g

Epilepsy Foundation Northwest - <https://epilepsyoregon.org/support>
Offers parent support group every other month in Vancouver. For those w for parent support coordinator.

Hands and Voices of Oregon - www.handsandvoices.org 541-241-
Support and information for all Oregon families raising children who are D methods and technologies are supported.

Oregon Family Support Network - www.ofsn.org - 503-362-8068
Supports families who are raising children with significant mental health advocacy throughout Oregon.

Reach Out Oregon - www.reachoutoregon.org 833-732-2367
Website, live chat, or email support for parents of youth with emotional

Swindells Resource Center - <http://oregon.providence.org/our-service>
541-732-5958 (Spanish) 503-215-2429 (English)
Books, resources, free care notebooks for families, telephone support, stat special needs, parenting classes, and much more.

United Cerebral Palsy - <http://www.ucpsaorwa.org/our-services/famil>
Serves families whose children experience disabilities that mimic C diagnosis of CP. Conferences, trainings, parent support, "Respitatio

This is a partial list; see reverse for more family programs. Call 855-323-

Rev 3-15-2020 X:\OHSU Shared\Health\Research\OCCYSHN\FIN and ORF3FHIC\ORF3FHIC\T Approved - Rebranded

OREGON FAMILY TO FAMILY HEALTH INFORMATION CENTER

The Oregon F2F HIC recommends the following Oregon Family Networks. The following organizations are staffed during regular business hours and can respond to Spanish speaking callers immediately or within a short period. Funded by the Oregon Council on Developmental Disabilities.

Multnomah, Clackamas, Washington, Clatsop, Tillamook, Lincoln, Columbia Counties
FACT Oregon 888-988-3228
Website: www.factoregon.org
Facebook Page: <https://www.facebook.com/FACToregon>

Yamhill, Polk, Marion Counties
Creating Opportunities 503-559-0424
Website: www.creatingops.org
Facebook page: <https://www.facebook.com/2CreateOpportunities>

Lane County
Families Connected 541-343-5256
Website: <https://arclane.org/>
Facebook page: <https://www.facebook.com/FamiliesConnectedCommunityCalendar>

Deschutes, Crook, Jefferson Counties
Central Oregon Disability Support Network 541-548-8559
Website: <http://www.codsn.org/>
Facebook page: <https://www.facebook.com/CODSN/>

Baker County - **Community FORCE Family Network** 541-406-8983 or 541-609-0533
Website: www.CommunityForceFN.org
Facebook page: <https://www.facebook.com/Community-FORCE-242467526463029/>

Douglas County
FEATT Family Network 541-670-2750
Website: <http://www.featt.org/>
Facebook page: <https://www.facebook.com/FEATT-719811931401633/?fref=pb>

Klamath County - **Family Advocacy & Support Network (FASN)** 541-591-5507 or 541-880-4863
Website: www.FASNfamilynetwork.org
Facebook page: <https://www.facebook.com/FamilyAdvocacyandSupportNetwork/>

Harney County - **Kintsugi Disability Support Network** 541-238-2263 or 541-241-8989
Website: <http://www.kidsupportnetwork.org/>
Facebook page: <https://www.facebook.com/KintsugiDisabilitySupportNetwork>

Jackson and Josephine Counties - **Bridging Communities** 541-690-8542
Website: <https://livingops.org/bridging-communities>
Facebook Page: <https://www.facebook.com/bcoregon>

This is a partial list; see reverse for more family programs. Call 855-323-6744 for more information.

The Oregon Family to Family Health Information Center is affiliated with the Oregon Center for Children and Youth with Special Health Needs, Oregon Health & Science University, and supported by the Health Resources and Services Administration (HRSA) of the US Department of Health and Human Services (HHS). Grant #5R01AC12059 (Family Professional Partnership/SPL705). The information, content and conclusions are those of the author(s) and should not be construed as the official position or policy of, nor should any endorsement be inferred by, HRSA, HHS, the US Government, or OHSU.

Rev 3-15-2020 X:\OHSU Shared\Health\Research\OCCYSHN\FIN and ORF3FHIC\ORF3FHIC\T Tip Sheets - Approved Rebranded\English Tip Sheets Approved - Rebranded

Community Hot Lines and Warm Lines

Why this resource? Both youth and parents need a place to talk to someone in the event of a mental health emergency and to learn more about their health concern and what is available.

Lines for Life YOUTHLINE

Teen-to-teen crisis and help line. Teen-staffed daily from 4-10pm (*adult staff will answer at other hours*)

Call: 877-968-8491

Text: teen2teen to 839863

Chat:

www.oregonyouthline.org

Lines for Life SUICIDE LIFELINE

Call: 800-273-8255
(always open: 24/7, 365)

Text:

273TALK to 839863
(8am-11pm daily)

Reach Out Oregon

Peer - Crisis, Listening, Support.
<https://www.reachoutoregon.org/>

OHSU's **TRANSGENDER HEALTH** **PROGRAM**

<https://www.ohsu.edu/transgender-health>

- Oregon support groups, crisis lines, support systems
- Info for finding mental health therapists
- Info for changing documents
- Classes/Events

Culturally Specific LGBTQ Services

Large resource list:

**[https://namior.org/resources/
community-resource-lists/culturally-
specific-services/](https://namior.org/resources/community-resource-lists/culturally-specific-services/)**



DOERNBECHER
CHILDREN'S
Hospital

OCCYSHN
Oregon Center for Children and
Youth with Special Health Needs

Understanding Risk and Protective Factors for Suicide



Understanding Risk and Protective Factors for Suicide: A Primer for Preventing Suicide

Risk and protective factors play a critical role in suicide prevention. For clinicians, identifying risk and protective factors provides critical information to assess and manage suicide risk in individuals. For communities and prevention programs, identifying risk and protective factors provides direction about what to change or promote. Many lists of risk factors are available throughout the field of suicide prevention. This paper provides a brief overview of the importance of risk and protective factors as they relate to suicide and offers guidance about how communities can best use them to decrease suicide risk.

<https://www.sprc.org/sites/default/files/migrate/library/RiskProtectiveFactorsPrimer.pdf>

YOUTH SUICIDE WARNING SIGNS

YOUTH

HEALTHCARE PROFESSIONALS

PARENTS/CAREGIVERS

<https://www.youthsuicidewarningsigns.org/>

**Recommended Standard Care
for People with Suicide Risk:**
MAKING HEALTH CARE SUICIDE SAFE

<https://theactionalliance.org/resource/recommended-standard-care>

Suicidality and Self Injury

HOME

FREE TRAINING & RESOURCES

ABOUT

TEAM

now
matters
now

CRISIS HELP

what is this?

suicidal thoughts

mindfulness

lethal means

<https://www.nowmattersnow.org/skills>



Cornell University
College of Human Ecology

<http://www.selfinjury.bctr.cornell.edu/resources.html>

Self-injury & Recovery Resources
(SIRR)



DOERNBECHER
CHILDREN'S
Hospital

OCCYSHN
Oregon Center for Children and
Youth with Special Health Needs

Family Experiences Monograph

Why this resource? Families can be a doctor's greatest partner in the diagnosis and treatment of a child patient; Understanding what families want in that partnership can be very helpful.

Ways to Make Families Feel Comfortable:



1. Resources
2. Private Area
3. Knowledgeable Staff
4. Supportive, Non-judgmental Staff
5. Screening Questionnaires, Checklists

Topics Families Want Addressed in Resources:



1. Mental Health & Illness
2. Action Steps
3. Services and Supports
4. Referrals
5. Behavioral Interventions

Top Five Most Helpful Comments:



1. There Is Hope
2. You Are Not Alone
3. It's Not Your Fault
4. I Understand
5. Your Child Has Many Strengths

Top Two Discouraging Comments:



1. Dismissive Comments
2. Blaming Comments

DO REMEMBER to check in on your choice of words.

Childhood and Family Trauma

Why this resource? Childhood Trauma is common. There is a direct link between childhood trauma and adult onset of disease. Trauma experiences range from neglect, abuse, exposure to traumatic events, loss of safety, and persistent toxic stress. Understanding how to recognize, treat and/or refer is paramount for health care and education professionals.



<https://www.nctsn.org/what-is-child-trauma/about-child-trauma>



<https://www.cdc.gov/violenceprevention/pdf/essentials-for-childhood-framework508.pdf>

WHAT ARE ACES?

AND HOW DO THEY RELATE TO TOXIC STRESS?

- <https://acestoohigh.com/got-your-ace-score/>
- <https://www.cdc.gov/violenceprevention/childabuseandneglect/aces/fastfact.html>
- <https://developingchild.harvard.edu/resources/aces-and-toxic-stress-frequently-asked-questions/>

Neuro Sequential Model of Therapeutics – Trauma Resources

Why this resource? Adverse Childhood Experiences and Traumatic Stress can have profound impact on brain development and treatment can work when adults work together.

Seven Slide Series Video: The Human Brain

14 minute online video created and narrated by Bruce D. Perry. Core concepts regarding brain structure and function are introduced providing the basis for developmentally sensitive and trauma-informed caregiving, education and therapy.

Perry, B.D., (The ChildTrauma Academy). (2013) 1: The Human Brain [Video webcast].

In Seven Slide Series. Retrieved from <https://www.youtube.com/watch?v=uOsgDkeH52o>

Seven Slide Series Video: Sensitization and Tolerance

10 minute online video created and narrated by Bruce D. Perry. An introduction to the crucial role that patterns of stress response system activation play in pathology and healing is discussed.

Perry, B.D., (The ChildTrauma Academy). (2013) 2: Sensitization and Tolerance [Video webcast].

In Seven Slide Series. Retrieved from <https://www.youtube.com/watch?v=qv8dRfgZXV4>

Seven Slide Series Video: Threat Response Patterns

12 minute online video created and narrated by Bruce D. Perry. The variety of adaptive responses that can be used under threat are introduced, with a focus on the hyperarousal and dissociative continuum.

Perry, B.D., (The ChildTrauma Academy). (2013) 3: Threat Response Patterns [Video webcast].

In Seven Slide Series. Retrieved from

<https://www.youtube.com/watch?v=sr-OXkk3i8E&feature=youtu.be>



- <https://youtu.be/FOCTxcaNHeg>

Materials on hard topics written for children, youth, families

Why this resource? Some things are really hard for parents to talk about. Some of these resources might help make it easier. Not all families will want handouts. Offer them anyway. Someone in the home may need them.

Easy-to-read downloadable tip sheets (English/Spanish)

- Raising your Kin
- Parenting after Domestic Violence
- Adoption
- Human Trafficking
- Helping children heal Stress
- Housing
- Food
- Many more



DOERNBECHER
CHILDREN'S
Hospital

OCCYSHN
Oregon Center for Children and
Youth with Special Health Needs

Raising Your Kin



What's Happening

No matter why or how they came to live with you, your relative's children will benefit from being in your home. When children cannot be with their parents, living with a family member may provide:

- Fewer moves from place to place
- The comfort of a familiar language, culture, and family history
- A chance to stay with siblings
- More contact with their parents, depending on the situation

What You Might Be Seeing

Despite these benefits, the children will face some unique challenges:

- They may feel insecure and unsure that you will take care of them.
- They may act out or challenge you.
- They will miss their parents.
- They may be anxious or depressed.
- They may seem young or act too old for their ages.

What You Can Do

It will take time for your relative's children to feel safe and secure in their new home with you. You can encourage these good feelings in a number of ways:

- Set up a daily routine of mealtimes, bedtime, and other activities.
- Help the children feel "at home" by creating a space just for them. Allow them to bring comfort items from home, such as bedding, stuffed animals, and photos or posters.
- Talk to the children, and listen when they talk to you.

- Set up a few rules and explain your expectations. Then, enforce the rules consistently.
- Reward positive behavior. When children make mistakes, focus on teaching rather than punishing.
- Be as involved with their school as you can, and encourage your children to participate in school activities.

This is a big job, and you may need help from your community. Here are some suggestions:

- Help with housing or other bills, clothing, or school supplies may be available in your community to help you meet the children's needs.
- Join or start a support group in your neighborhood. Often there are local kinship caregivers support groups.
- Ask for help and referrals from a church leader, the counselor at the children's school, or a social services agency.
- If necessary, get professional help to address any special needs your relative's children may have, such as medical care, mental health care, or special education. Use respite care if it is available.

For more information on support for kin raising children, visit Information Gateway's About Kinship Care web section at <https://www.childwelfare.gov/topics/outofhome/kinship/about/>.

Remember: Parenting a relative's child brings special challenges and special joys. Do not hesitate to ask for help or seek services in your community for yourself and your children.

This tip sheet was created with information from experts in national organizations that work to prevent child maltreatment and promote well-being. At <https://www.childwelfare.gov/topics/preventing/preventionmonth/resources/tip-sheets/>, you can download this tip sheet and get more parenting tips, or call 800.394.3388.

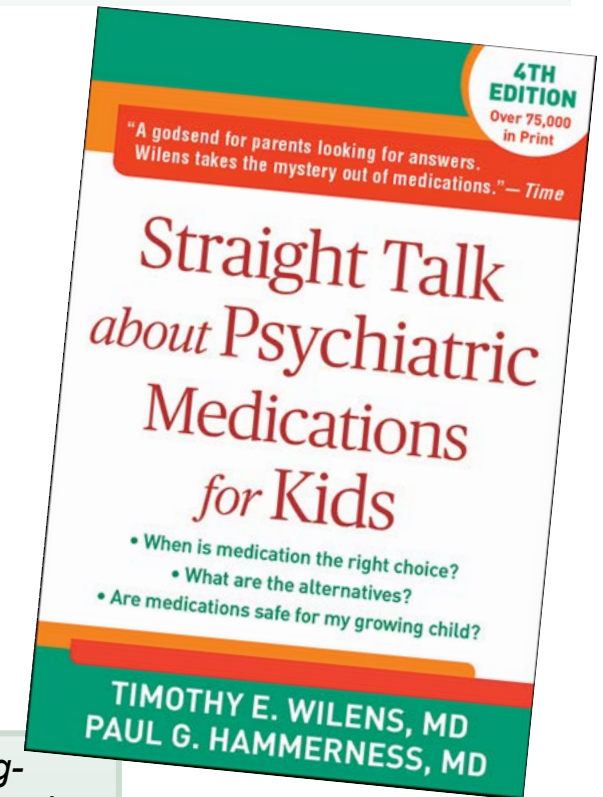
2019/2020 Prevention Resource Guide 85

[https://
www.childwelfare.gov/
topics/preventing/
preventionmonth/
resources/tip-sheets/](https://www.childwelfare.gov/topics/preventing/preventionmonth/resources/tip-sheets/)

Communication with Families about Psychiatric Medications

Why this resource? The decision to medicate one's child is a big one! Developing a positive and functional partnership between doctor and parents of a minor patient is imperative for success.

- **Take the time** to educate families on why you are recommending a particular medication and what the child has to gain;
- **Involve parents** in the overall treatment plan;
- **Be honest** with parents about the range of side effects the youth may experience. Parents need to be educated about how to recognize side effects and which ones warrant an immediate call to you, the prescribing doctor, or 911.
- **Parents should always be responsible for safe storage and administering medications! ***discuss safety planning*****



“Therapy and medications together may have a very powerful, long-lasting effect as compared to either treatment alone. Success depends on using the right kind of therapy and medication for the disorder and the specific, unique needs of the child, and often the family too.”

Parent Information about Complex Health Conditions

Why this resource? It can be very distressing to experience complex mental, emotional, developmental health concerns. Helping parents find reliable information can help.

Guides to:



[https://
childmind.org/](https://childmind.org/)

Parents Guide to Autism	Parents Guide to Problem Behavior	Parents Guide to Emergency Hospitalization	Parents Guide to Depression	Binge Eating Disorder Basics	Autism Spectrum Disorder Basics	ADHD Basics	
Anxiety Basics	Helping Children Cope With Grief	Parents Guide to OCD	Teachers Guide to Selective Mutism	Anorexia Nervosa Basics	Acute Stress Disorder Basics	Disruptive Behavior Disorders Basics	
Parents Guide to Dyslexia	Parents Guide to PANS and PANDAS	Helping Children Cope After a Traumatic Event	Teachers Guide to ADHD in the Classroom	Tourette's Disorder Basics	Substance Use Disorder Basics	Speech Sound Disorder Basics	Specific Phobia Basics
Teachers Guide to Anxiety in the Classroom	Teachers Guide to OCD in the Classroom	Parents Guide to ADHD Medications	Parents Guide to Eating Disorders in College	Specific Learning Disorder Basics	Social Communication Disorder Basics	Somatic Symptom Disorder Basics	Social Anxiety Disorder Basics
Parents Guide to Children and Multiple Medications	Parents Guide to Teenagers and Sleep	Parents Guide to ADHD	Parents Guide: How to Help a Child with Selective Mutism	Sleep-Wake Disorders Basics	Separation Anxiety Disorder Basics	Selective Mutism (SM) Basics	Schizophrenia Basics

More than 60 Guides for Parents!

ADHD Resources for Families

Why this resource? Families have many tricks up their sleeves to support one another. Helping them find each other for support and learning is a valuable service for all families and their children.

CHADD

[Children and Adults with Attention Deficit/Hyperactivity Disorder](#)

30+ years

Local groups:

[Portland/Milwaukee](#)

(Website not fancy!)

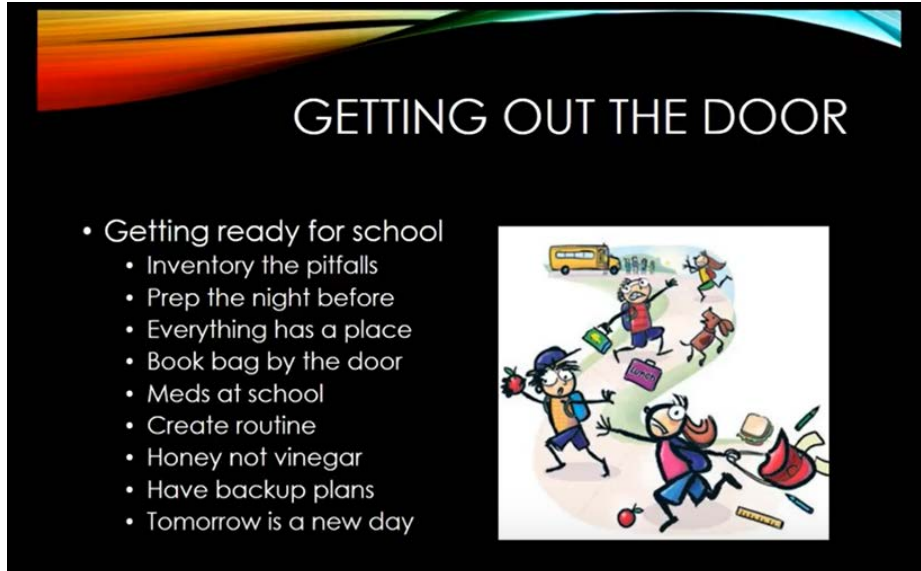
On-line community:

[ADHD Parents Together](#)

(attractive, moderated, easy to use, current)

25+ [family fact sheets](#) on various topics
(two included in resource section of ECHO portal)

When you and your child both have ADHD
[YouTube Videos](#)



GETTING OUT THE DOOR

- Getting ready for school
 - Inventory the pitfalls
 - Prep the night before
 - Everything has a place
 - Book bag by the door
 - Meds at school
 - Create routine
 - Honey not vinegar
 - Have backup plans
 - Tomorrow is a new day

Trauma, Stress, Distress

Why this resource? Trauma, stress, distress all impact our brains, and in turn how we think, feel and behave. Understanding that “behavior” is our communication of what is happening for us inside.

NeuroSequential Model + Collaborative Problem Solving

Dr. Perry and Dr. Ablon talk about how their models can help during the COVID-19 crisis.

Link:

[https://](https://www.neurosequential.com/covid-19-resources)

www.neurosequential.com/covid-19-resources

NN COVID Series: 1 - Patterns of Stress determine Risk & Resilience (15 min)

<https://youtu.be/orwln02h6V4>

NN COVID Series: 2 - Understanding State-dependent Functioning (20 min) video with Dr. Bruce Perry reviews how stress and distress change the way we think, feel and

behave. <https://youtu.be/PZg1dlskBLA>

NN COVID Series: 3 - Emotional Contagion (20 min) <https://youtu.be/96evhMPcY2Y>

NN COVID Series: 4 - Sequence of Engagement (20 min) Regulate-Relate-Reason can help minimize miscommunication and behavioral challenges (especially with dysregulated adults and children). <https://youtu.be/LNuxy7FxEVk>

NN COVID Series: 5 - Understanding Regulation (20 min)

<https://youtu.be/L3qlYGwmHYY>

NN COVID Series: 6 - Dosing & Spacing <https://youtu.be/5ATSI8XhF-k>



DOERNBECHER
CHILDREN'S
Hospital

OCCYSHN
Oregon Center for Children and
Youth with Special Health Needs

Collaborative Problem Solving

Why this resource? “Kids do well when they can.” (and so do parents, doctors, teachers....)

Collaborative Parents Oregon

When: Ongoing!

What: Erin Middleton, Certified trainer Shannon Pugerude, and other members of the certified community have been posting all kinds of things for families.

Link: Go to the **Collaborative Parents Oregon** page on **Facebook**

Collaborative Problem Solving Office Hours

When: Every Wednesday night from 6-7pm PST

What: The Oregon CPS Project at OHSU holds these office hours to provide support to caregivers who want help managing challenging behaviors in their homes. All parents are welcome, regardless of training or CPS knowledge. We are here to help! Drop by at any point during the hour; we'll be there!

Link: <https://zoom.us/j/277305240>

Social Distance Coffee Club

When: Every Friday morning at 8am

What: Certified Trainer Jordan Spikes hosts this informal gathering for the CPS community for coffee, community and maybe some Collaborative Problem Solving. The goal is connection. Check it out!

Link: <https://us04web.zoom.us/j/565977322>

Online Intro to CPS

When: Tuesday, May 5, from 12-2pm PST

What: This very broad, basic overview of the CPS model is sponsored by the Oregon Health Authority and is free of charge to Oregonians. All levels of learning and all populations welcome. Do you know anyone who needs some training in the basics of CPS? Do you want a quick refresher? Sign up!

Link:

<https://www.eventbrite.com/e/online-intro-to-collaborative-problem-solving-tickets-97848105317>



DOERNBECHER
CHILDREN'S
Hospital

OCCYSHN
Oregon Center for Children and
Youth with Special Health Needs

Autism Spectrum Disorder (ASD)

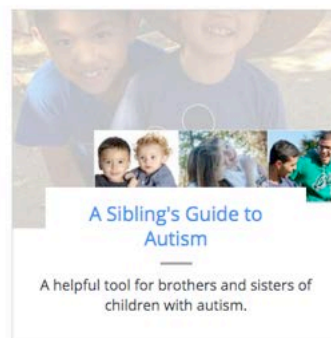
According to the Centers for Disease Control, [autism affects an estimated 1 in 54 children](https://www.cdc.gov/ncbddd/autism/facts.html) in the United States today.



<https://www.autismspeaks.org/>

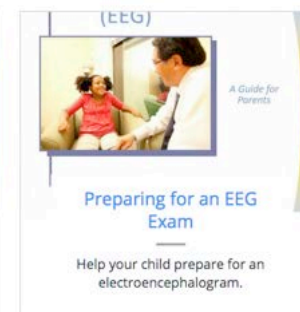
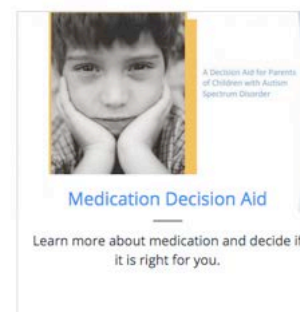
Family Support

Resources to support family members of people with autism.



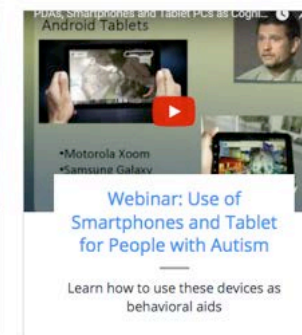
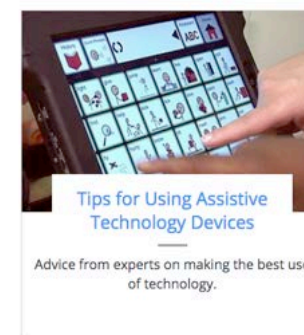
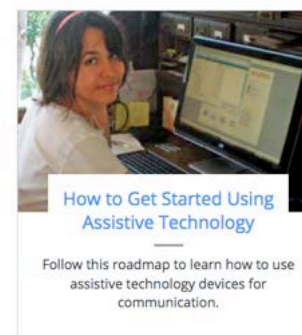
Medical Resources

Resources to assist people with autism and additional medical needs.



Technology

Resources to teach you how to use technology most effectively.



Sensory Integration and Learning Disorders



New Edition, Parent Friendly
“Best book on the subject”

https://www.amazon.com/dp/0874244374/ref=cm_sw_r_em_api_i_c_XV5NEb7ZWG95A

The infographic is titled 'ADHD and Coexisting Conditions: Neurodevelopmental Disorders' and is from CHADD's National Resource Center on ADHD. It states that 'More than two-thirds of individuals with ADHD have at least one other coexisting condition.' The infographic is divided into four sections, each with a puzzle piece icon:
1. **AUTISM**: Prevalence: 1 out of 4. Symptoms: Overfocused, unable to shift attention; Low tolerance for change; Highly sensitive or insensitive to light, noise, touch, pain, smell, or taste; Food preferences based on color or texture; Often able to remember detailed facts. Treatment Options: Behavior therapy including parent training; Skills training to cope with daily life; Medication for ADHD symptoms or irritability; Dietary therapy to eliminate nutritional gaps.
2. **LEARNING DISORDER**: Prevalence: 1 out of 2. Symptoms: Trouble processing information; Reading difficulty (dyslexia); Handwriting difficulty (dysgraphia); Math calculations difficulty (dyscalculia). Treatment Options: Learning accommodations and modifications; Special education services.
3. **SPEECH PROBLEMS**: Prevalence: 1 out of 10. Symptoms: Issues with word or sound pronunciation; Stuttering; Articulation. Treatment Options: Speech therapies.
4. **TOURETTE SYNDROME**: Prevalence: 1 out of 10, but more than 2 out of 3 children with Tourette's have ADHD. Symptoms: Motor tics; Vocal tics. Treatment Options: Medication; Behavior therapy; School supports and accommodations.
The infographic also includes the CHADD logo and the website <https://chadd.org/>. A small disclaimer at the bottom states: 'This infographic is supported by Cooperative Agreement Number NU38D000002-01-00 from the Centers for Disease Control and Prevention (CDC). The contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.'

<https://chadd.org/>

Research | Information Library | Fact Sheets & Infographics
Resources for professionals, parents, etc.

Limited Language and Social Skills Support

- Social interactions may be especially difficult for children with an autism spectrum disorder, adhd, or other social delay.
- Many children, especially those diagnosed with an autism spectrum disorder, Down syndrome and other special need, often fail to pick up on social cues, making learning a social skill especially difficult.
- Social stories may increase awareness and maintenance of social skills.



<https://apps.apple.com/us/app/social-story-creator-library/id588180598>

Depression

Why this resource? Depression is common, it can affect every aspect of one's life, it often profoundly impacts relationships with family members and other loved ones, and it is treatable.



[https://
www.dbsalliance.org/
education/depression/](https://www.dbsalliance.org/education/depression/)

Support

- Crisis
- COVID-19 Resources
- Depression and Bipolar Support Groups
- Online Support Groups
- Supporting Youth Mental Health
- Young Adults
- Support for Friends & Family
- Balanced Mind Parent Network

Education

- Depression
- Bipolar Disorder
- Anxiety
- Screening Center
- Co-Occurring Illnesses
- Related Concerns

More

- Resources for Clinicians
- Frequently Asked Questions



<https://namior.org/programs/>

Eating Disorders

Why this resource? Eating disorders are complex and affect all ages, genders, races and ethnic groups. Treatment and support can include family members and other social supports of the individual.



The National Eating Disorders Association (NEDA) is the largest nonprofit organization dedicated to supporting individuals and families affected by eating disorders.

Eating Disorders Screening Tool

This short screening — appropriate for ages 13 and up — can help determine if it's time to seek professional help.

[Get Started](#)

[https://
www.nationaleatingdisorders.org/](https://www.nationaleatingdisorders.org/)

Eating Disorders

CORE VALUES

ANAD is committed to providing free services that are accessible to all.

ANAD demonstrates openness and inclusivity by respecting every part of the eating disorder recovery journey.

ANAD approaches every interaction with compassion and patience.

ANAD promotes self-care and well-being throughout our community.

ANAD believes in the power of community and long-term relationships.

Through teamwork and education, ANAD will find help for anyone.

The National Association of Anorexia Nervosa and Associated Disorders, (ANAD) is a non-profit (501c3) organization working in the areas of support, awareness, advocacy, referral, education, and prevention of eating disorders.



<https://anad.org/>

Eating Disorders Helpline

Eating Disorder Screening Tool

About Our Support Groups

Treatment Directory

Grocery Buddies

Request a Mentor

RECOVERY Stories

Safety & Depression | Safety & Eating Disorders

Why this resource? **Depression and Eating Disorders can increase risk of suicide.**



[https://
www.henryford.com/blog/
2017/07/depression-
primary-care-know](https://www.henryford.com/blog/2017/07/depression-primary-care-know)

Search
“Perfect Depression Care”
for scholarly articles



Eating Disorders

Eating Disorders and Suicide

Midlife (Eating Disorder) Crisis

Eating Disorders in Women

Eating Disorders in Children

Eating Disorders in Men

Eating Disorder Treatment

<https://www.psycom.net/>

PSYCOM was founded by psychiatrist and psychopharmacologist Ivan K Goldberg, MD

- a **discussion group for clinicians** who could use it to share and exchange information and advice;
- site has evolved into a highly-regarded and trusted mental **health resource for consumers**;
- eating disorders, bipolar disorder, ADHD, obsessive-compulsive disorder, schizophrenia, depression, and generalized anxiety disorder.



DOERNBECHER
CHILDREN'S
Hospital

OCCYSHN
Oregon Center for Children and
Youth with Special Health Needs

Remember to reference your Resources about Suicide Safety

Safety & Depression | Safety & Eating Disorders

Additional Resources

From a participant:

CREDN
(Columbia River Eating
Disorder Network): annual
conferences and other
provider resources.

AAFP article that I've found
to be so helpful in the past:
[https://www.aafp.org/afp/
2015/0101/p46.html](https://www.aafp.org/afp/2015/0101/p46.html)

Oregon Runaway and Homeless Youth

<https://www.oregon.gov/DHS/CHILDREN/Homeless-Youth/Pages/index.aspx>

National Links

[United States Interagency Council on Homelessness \(USICH\)](#)
[National Alliance to End Homelessness \(NAEH\)](#)
[Point Source Youth \(PSY\)](#)
[National Network for Youth \(NN4Y\)](#)
[National Center for Homeless Education \(NCHE\)](#)
[National Association for the Education of Homeless Children
and Youth \(NAEHCY\)](#)
[True Colors Fund](#)
[SchoolHouse Connection](#)
[National Law Center on Homelessness and Poverty \(NLCHP\)](#)
[Youth Homeless Demonstration Program \(YHDP\)](#)

Local Links

[Annual Point in Time \(PIT\)](#)
[Continuums of Care \(CoC\)](#)
[McKinney-Vento Homeless Education Program](#)
[Oregon Youth Development Council](#)
[Joint Office of Homeless Services – Multnomah
County](#)
[Homeless Management Information System
\(HMIS\)](#)
[Safety, Oversight, and Quality Unit \(Licensing\)](#)
[Child Welfare Independent Living Program
\(ILP\)](#)

Remember to reference your Resources about Suicide Safety



DOERNBECHER
CHILDREN'S
Hospital

OCCYSHN
Oregon Center for Children and
Youth with Special Health Needs

Anxiety in Children, Teens, Young Adults

Why this resource? Helping parents with information about anxiety can help them to respond to their children in helpful ways. Learning to recognize behaviors that may indicate anxiety, how to respond, and when to seek help are important skills and knowledge.



National Institute
of Mental Health

Signs
Symptoms
Treatments
(Multiple Anxiety Disorders)

<https://www.nimh.nih.gov/health/topics/anxiety-disorders/>



Anxiety in Children, Youth, Adults
Information & Tools
Online Lessons
Downloadable Resources

<https://www.anxietycanada.com/>



DOERNBECHER
CHILDREN'S
Hospital

OCCYSHN
Oregon Center for Children and
Youth with Special Health Needs

Remember to Reference your Resources about Suicide Safety

Anxiety: Coping Skills for Parents and Young Children

Why this resource?

Help parents and their children learn coping skills to use between treatment sessions.

Anxiety Relief: 3 Activities to help Kids Manage Their Anxiety

<https://pro.psychcentral.com/child-therapist/2014/08/anxiety-relief-3-activities-to-help-kids-manage-their-anxiety/>

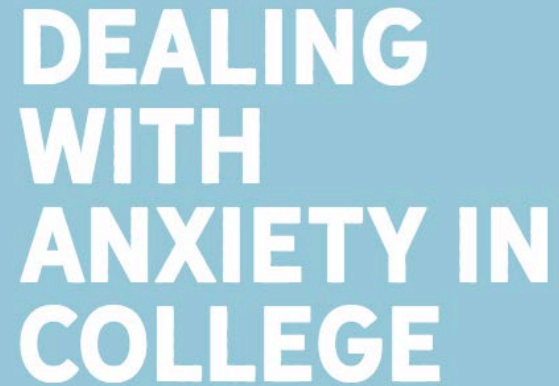


<https://copingskillsforkids.com/calming-anxiety/>

Anxiety in Young Adults

Why this resource? Anxiety is the most common mental health diagnosis in college students.

As youth transition into adulthood, parents are also learning how to balance support, availability, and increasing autonomy.

A blue rectangular graphic with the text "DEALING WITH ANXIETY IN COLLEGE" in white, bold, sans-serif capital letters, arranged in four lines.

<http://www.bu.edu/today/series/mental-health-matters/>

<https://buckeyerecoverynetwork.com/college-anxiety-guide/>

Substance Use | Substance Use Disorders

Why this resource? Helping parents with information about substance use and substance use disorders can illuminate the connections between mental health conditions and substance use.

Advice from experts and perspective from families who have been impacted by substance use.

<https://drugfree.org>



Learn From Parents Who Have Been There

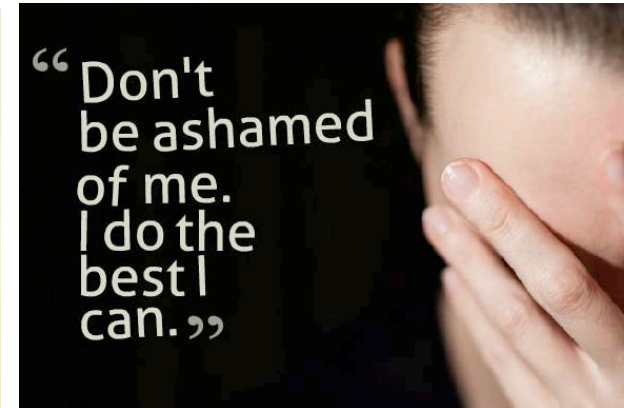
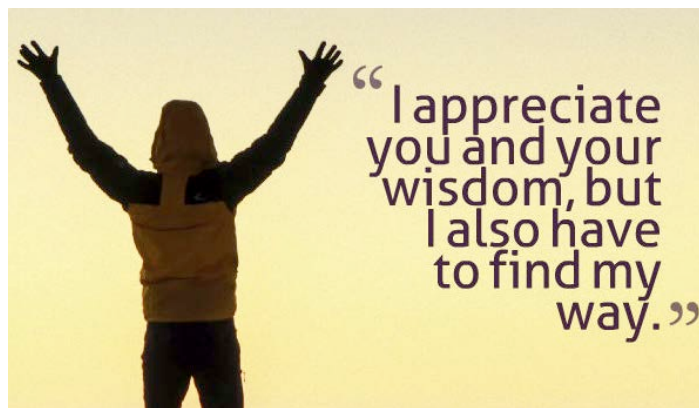
Learn from and find community among other parents who have been there. Read stories and first-hand accounts on the [Parent Blog](#), and depending on your individual circumstances, [connect with a Parent Coach for one-on-one support](#).

[LEARN MORE](#)

Anxiety and Substance Use Disorders

Why this resource? Parents can carry a lot of guilt and confusion about what they did and didn't do for their children in the process of discovering a mental health (including substance use) condition.

22 Things People With Mental Illness Wish Their Parents Knew



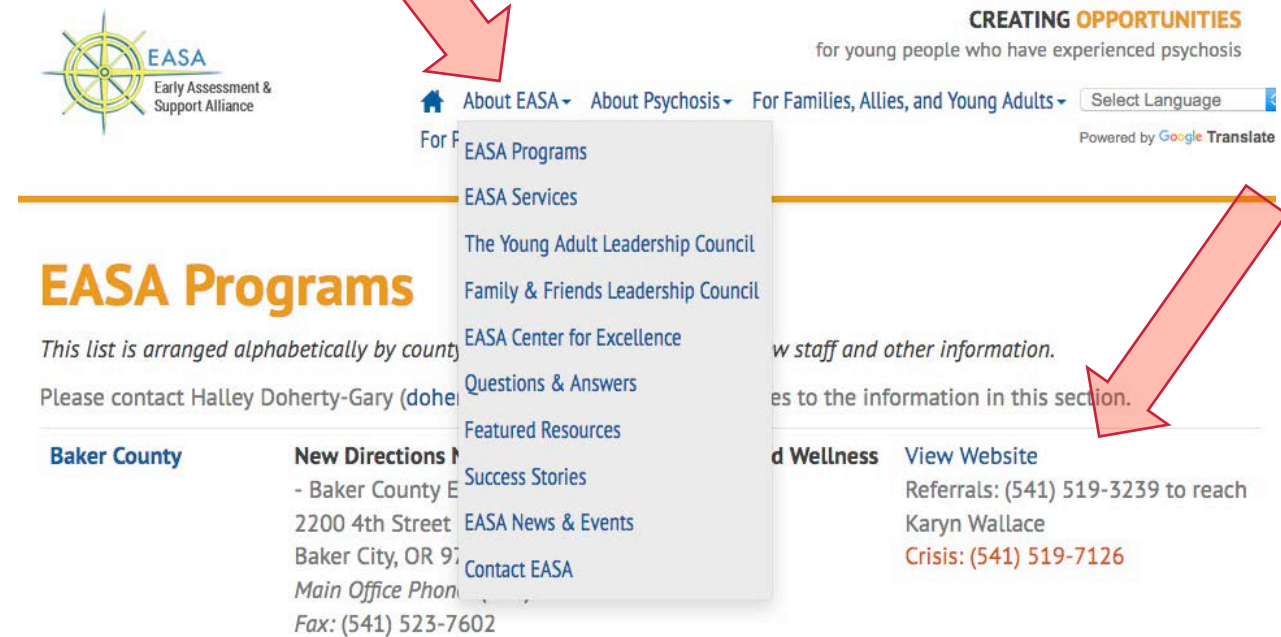
<https://themighty.com/2016/03/22-things-people-with-mental-illness-wish-their-parents-knew1/>

Psychosis: Assessment, Treatment, Support

Why this resource? Getting evaluation, treatment and support at the earliest stages of psychosis (and high clinical risk for psychosis-related disorders) can make a critical difference in a young person's life.

EASA

- Early Assessment and Support Alliance
- Network of programs across Oregon
- Serve teenagers, young adults experiencing early signs of psychosis and their families
- Include clinical high risk and bipolar-related psychosis



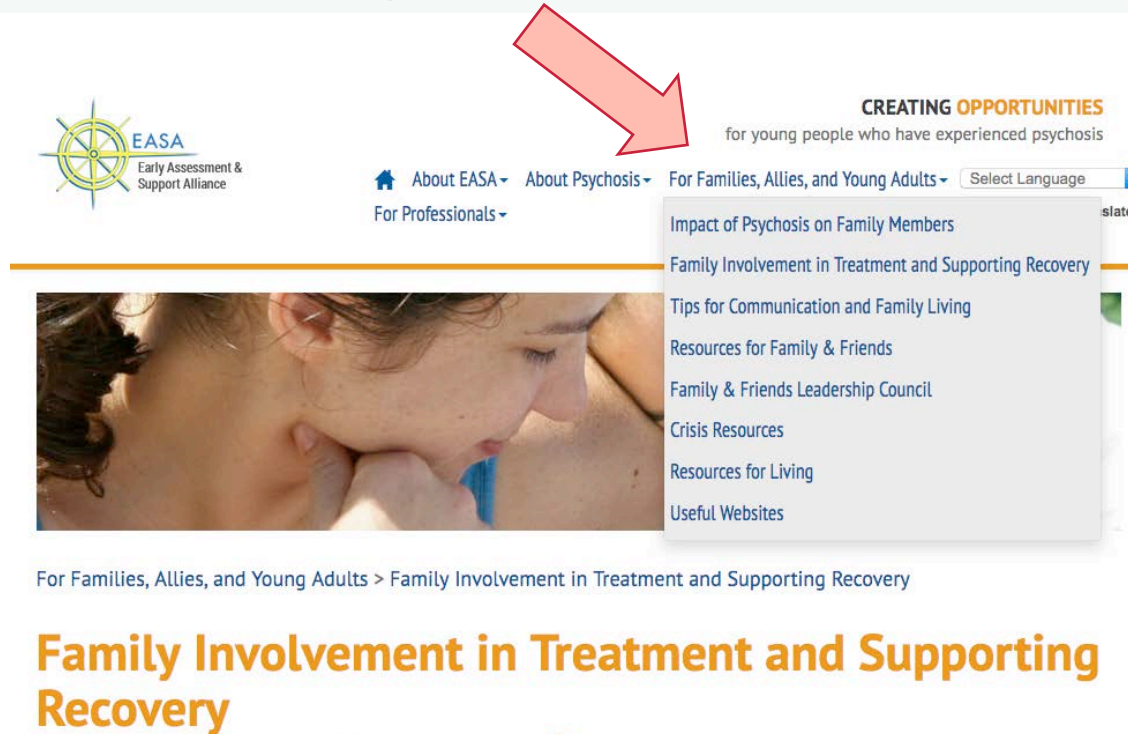
EASA Provides:

rapid identification, assessment, treatment and support

<http://easacommunity.org>

Psychosis: Family Support

Why this resource? Family education and support enables families to understand what their youth is experiencing and helps them to preserve supportive relationships.



- **Family psychoeducation**
- **Resources**
- **Connection with other families going through similar circumstances**
- **Family Involvement in Treatment**

<http://easacommunity.org>

EASA: Oregon's Leading Resource for Psychosis-Related Disorders

Why this resource? For providers, getting accurate, timely, research-based information is key to getting patients connected to appropriate resources.

EASA Center for Excellence

The EASA Center for Excellence is part of the OHSU-PSU School of Public Health. With support from the university and Oregon Health Authority, "EASA C4E" is a nationally recognized research and technical assistance program for early psychosis intervention programs across the United States.

[Learn more about EASA vs. EASA Center for Excellence >>](#)

Our Mission:

EASA C4E improves services for individuals with early psychosis and their families.

Supports local county EASA programs throughout Oregon

Provides training to providers

Technical assistance based on current research

International renowned expert team

Bipolar Disorder



<https://namior.org/>

Classes
Support groups
Advocacy
Affiliates in most counties



[https://
www.dbsalliance.org/
education/bipolar-disorder/](https://www.dbsalliance.org/education/bipolar-disorder/)

Thriving with Bipolar

In order to thrive, all aspects of a person must be evaluated including physical health, lifestyle, education, employment status or career goals, relationships, etc. Collaboration between health care providers and patients/clients is key to the future of treatment of mental health conditions if we hope to evolve to a person- or wellness-centered, whole-health approach.

Remember to Reference your Resources about Suicide Safety

Bipolar Disorder

Education and training on practical communication tools designed to build bridges and partnerships with persons who hold views of their illness and needs that are opposite to that of their loved ones, doctors, and sometimes even law enforcement.

Listen, Empathize, Agree, Partner

<http://dramador.com/>



DOERNBECHER
CHILDREN'S
Hospital

OCCYSHN
Oregon Center for Children and
Youth with Special Health Needs

DR. XAVIER AMADOR

About Speaker TV Psychologist News Expert Books & DVDs » Researcher Forensic

NEW AUDIOBOOK!

*"I know of no other book even in the same league."
Gerry Spence, Author of the NY Times Best-Seller How to Argue and Win Every Time*

**I AM NOT SICK
I Don't Need Help!**

How to Help
Someone with
Mental Illness
Accept
treatment

Xavier Amador, Ph.D.

LISTEN TO NEW RESEARCH & ADVICE FROM DR. AMADOR!

We are proud and excited to announce the publication of the first ever audio edition of: "I am not sick I don't need help!" How to help someone with mental illness accept treatment, by Dr. Xavier Amador (Vida Press, 2016).

Narrated by Dr. Amador, this edition includes additional new material not included in the 10th anniversary edition of the book! Like the best selling print versions of the book, the audiobook is for both Doctors/Therapists and Family Members.

Dr. Amador took special pains to add additional new advice on how to use the LEAP method to overcome resistance, anger, paranoia, and even estrangement from loved ones and patients who become isolated

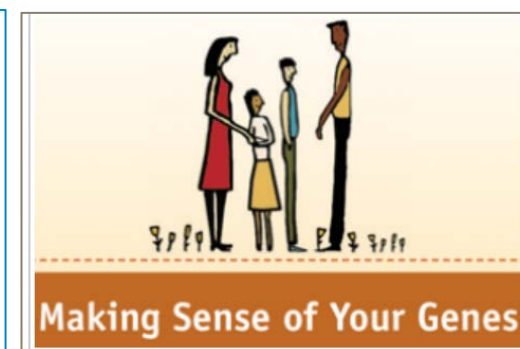
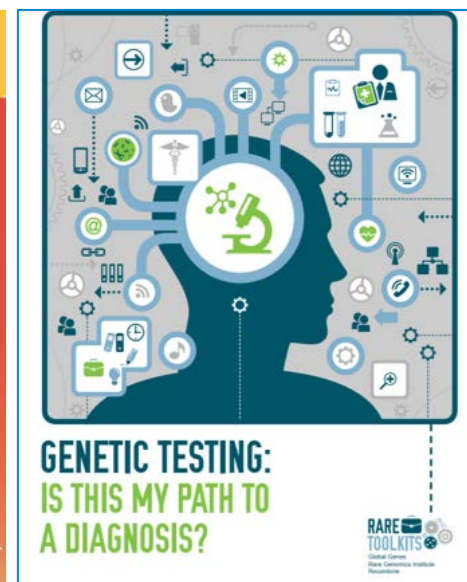
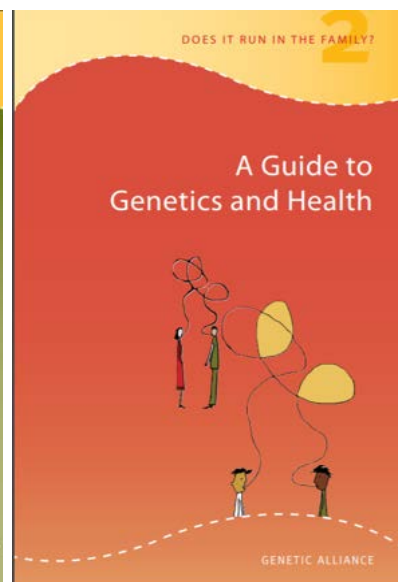
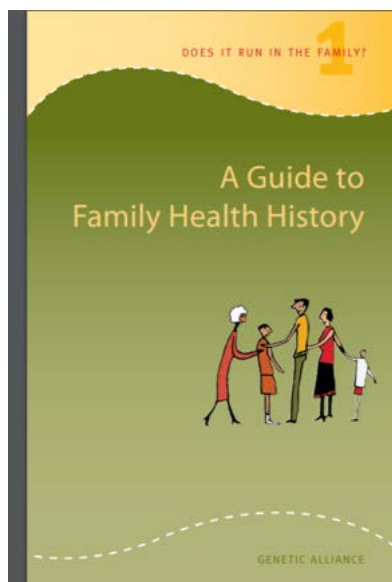
from the people who most want to help them.

Genetic Testing

Why this resource? Families are often confused when the subject of genetic testing comes up. Many have an immediate negative feeling about it because it has not been presented well. Concerns are often around privacy, involving other family members, and a fear that others are trying to influence their personal reproductive choices.

[Oregon Family to Family Health Information Center](#)

Parent Partners have training on genetics services. They can send these toolkits to families and support them in getting their questions answered.



oregonfamilytofamily.org
geneticalliance.org/resources/publications
globalgenes.org

Medications: Prescribing & Deprescribing

Why this resource? Remember the NAMI Monograph from Week 3 about what families want? Resources, resources, resources....

Guides - Articles - Tipsheets
Written for Parents



[https://
childmind.org/](https://childmind.org/)

Medication

—
Is Your Child Getting the Right Medication Dosage?

—
How to Take Kids Off Medication

—
When to Worry About Kids Taking Multiple Medications

—
<https://childmind.org/topics/concerns/medication/>

Prescription Financial Assistance

Why this resource? Finding a way to pay for costly prescriptions can present a hardship for families – thinking ahead about how a family will maintain their child's medications will help!

NeedyMeds is a great resource for funding prescription medications. It is a searchable database for individual drugs, clinical trials, etc. and also offers valuable information for parents:

www.Needymeds.org

Another resource for people dealing with medical debt due to the high costs of medications:

www.dollarfor.org

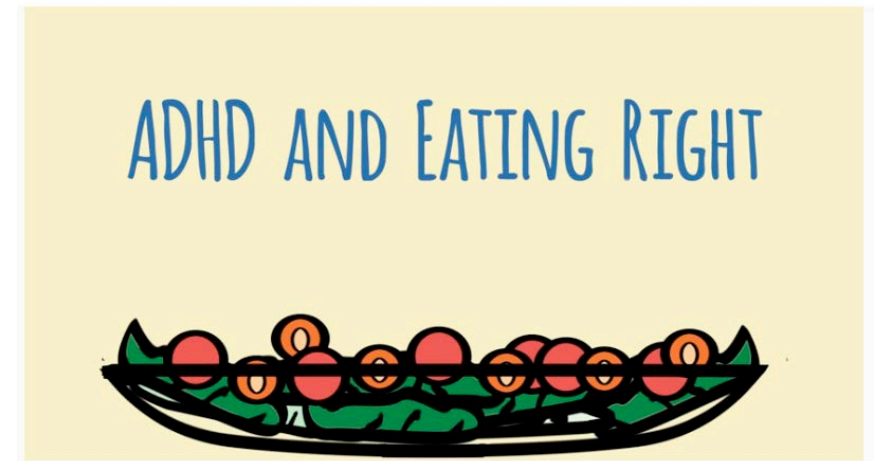
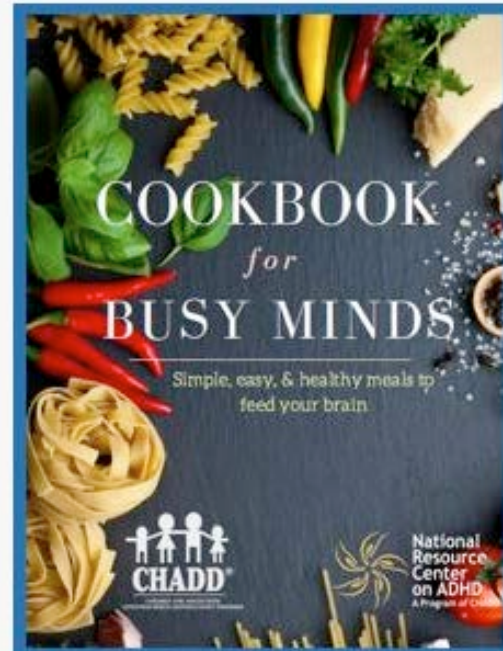
Nutritional Interventions

Why this resource? Families seek treatments that they view to be safer or more natural than prescription medications. This is a natural protective instinct, not necessarily an oppositional one. These resources can help families who are researching nutritional interventions.



www.trustortrash.org

An interactive tool to help families sort through the credibility of health information.



<https://chadd.org/about-adhd/nutrition-and-adhd/>

https://chadd.org/wp-content/uploads/2019/03/Cookbook_for_Busy_Minds.pdf

“Family Engagement”

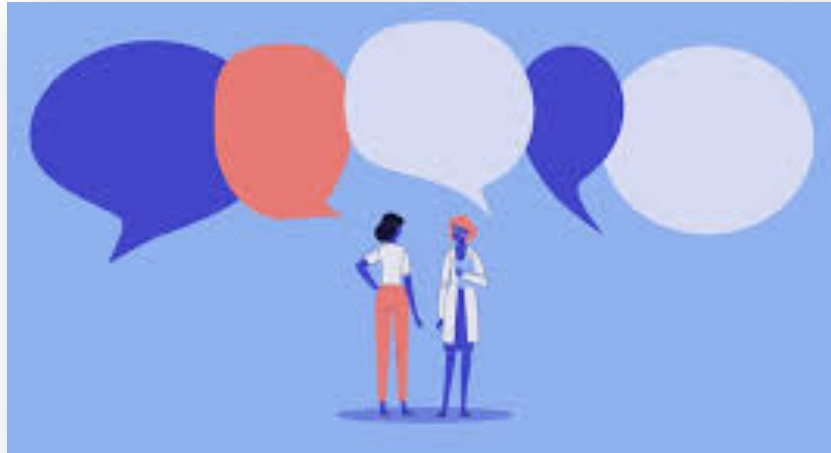
Why this resource?

Family engagement is really just “engagement.” How doctors and other health care providers approach relationship with their minor patients’ families can make the difference between a family that feels welcome and respected and one that is uncertain about how to work with you. The following slides will touch on factors that help build effective partnerships that ultimately benefit the youth.

Family Engagement ↔ Physician Engagement

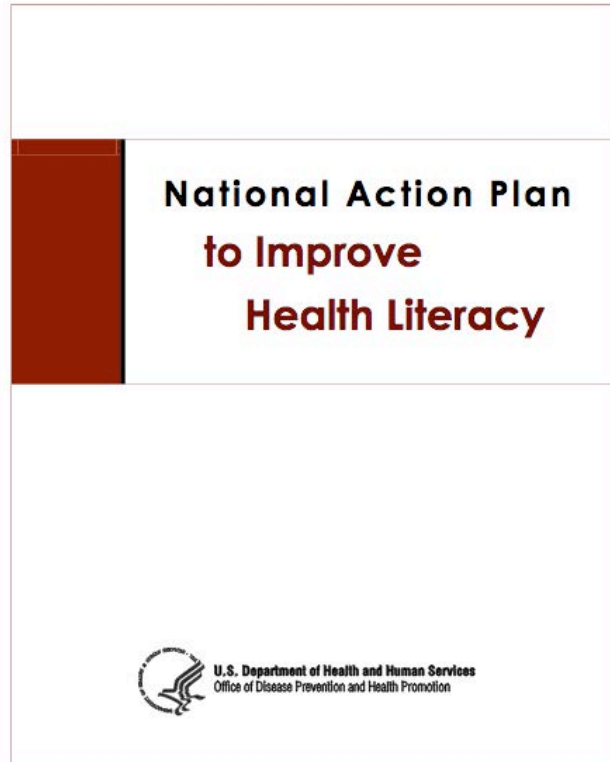
Why this resource? Looking closely at factors that can impact an effective relationship with your minor patient's parents/guardians can improve outcomes for your patient.

Many factors can influence an effective Family-Physician partnership:



- Established Trust
- Health Literacy
- Shared Understanding of Confidentiality and Consent to Care
- Effective Communication

What is Health Literacy?



✓ The degree to which individuals have the capacity to **obtain, communicate, process, and understand** basic health information and services needed to make appropriate health decisions.

<https://www.hrsa.gov/about/organization/bureaus/ohe/health-literacy/index.html>

✓ The skills of health professionals to **provide health information appropriate for their audience** is equally important.

https://health.gov/sites/default/files/2019-09/Health_Literacy_Action_Plan.pdf

Health Literacy

Health literacy is a **complex phenomenon** that involves **skills, knowledge, and the expectations** that health professionals have of one's understanding of health information and services.

Health information and services are **often unfamiliar, complicated, and technical**, even for people with higher levels of education.

People of **all ages, races, incomes, and education levels**—not just people with limited reading skills or people for whom English is a second language—are affected by limited health literacy.

According to research from the U.S. Department of Education, **only 12 percent of English-speaking adults in the United States have proficient health literacy skills.**

The impact of limited health literacy disproportionately affects lower socioeconomic and minority groups.

https://health.gov/sites/default/files/2019-09/Health_Literacy_Action_Plan.pdf

Trauma and stress also affect one's health literacy and capacity to take in and act on new information.

Shared Understanding: Legal Aspects of Health Care Communication

Minor Rights: Access and Consent to Health Care

A resource for providers, parents and educators



Not a legal document.

Health care providers can find themselves in a challenging position between honoring their minor youth's request to keep information private from their parents and honoring the parent's desire to be informed about their young person's care.

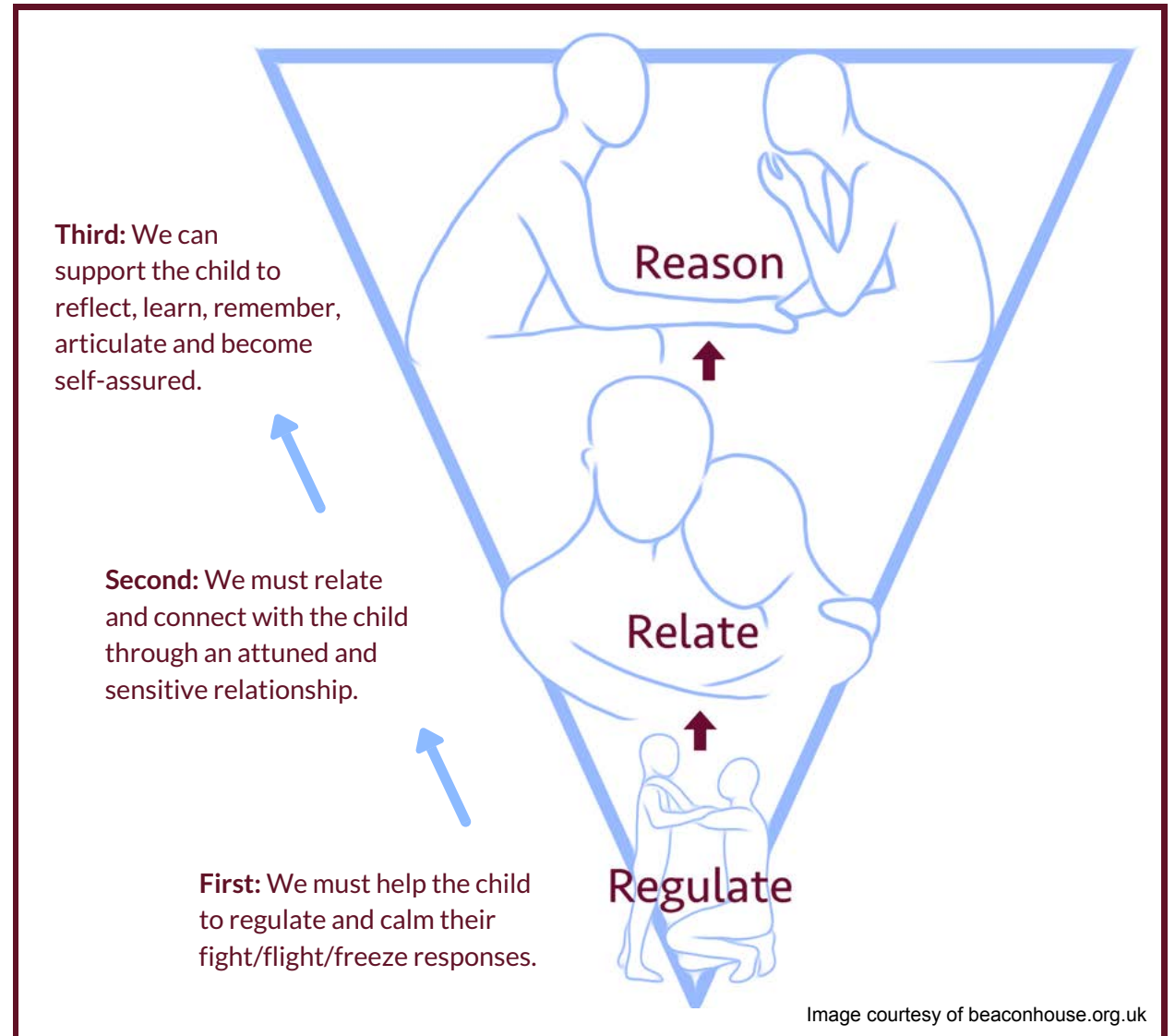
- **HIPAA** (health)
- **Confidentiality**
- **Release of Information (ROI)**
- **Informed Consent to Care**
- **42CFR** (substance use disorder treatment)
- **FERPA** (education)

<https://www.oregon.gov/oha/ph/HealthyPeopleFamilies/Youth/Documents/minor-rights.pdf>

Establishing Trust

Dr Bruce Perry, pioneering neuroscientist in the field of trauma, has shown that approaching your relationship with a vulnerable child using this simple sequence can help the child to learn, think and reflect.

- This same approach holds true for all of us with a nervous system.
- Parents often interact with their child's doctor while in a state of distress, confusion, fear, or frustration.



Heading straight for the 'reasoning' part of the brain with an expectation of learning, will not work so well if the child is dysregulated and disconnected from others.

Communication

Let's admit it, it's complicated!

Health care communication is a skill that is critical to safe and effective medical practice; it can and must be taught.

Communication skill influences patient disclosure, treatment adherence and outcome, adaptation to illness, and bereavement.



- Listening for Understanding
- Pace and Pattern of Conversation
- Tone of Voice
- Body Language
- Facial Expressions
- Choice of Words

Communicating With Children and Families: From Everyday Interactions to Skill in Conveying

Distressing Information: <https://pediatrics.aappublications.org/content/pediatrics/121/5/e1441.full.pdf>

<https://www.psychologytoday.com/us/blog/language-in-the-mind/202001/how-does-communication-work>

Some helpful phrases

“I just shared a lot of information, what questions do you have?”

“This is a lot to take in on the spot, would you like to think about it before making a decision?”

“What concerns are coming up for you?”

“Is there something else I can share before you feel comfortable in deciding on next steps?”

😊 **Friendly Reminder:**

- You are partnering with the family in regard to their child’s well-being.
- The family hopefully has many other valuable partners, as well.

Thank you for this opportunity to share these family resources with you!

Compiled by:

Julie Magers, BA

OHSU Child & Adolescent Psychiatry Division

magersj@ohsu.edu

Tamara Bakewell, MA

Oregon Center for Children and Youth with Special Health Needs (OCCYSHN)

bakewell@ohsu.edu