

A PRACTICAL PARENT'S GUIDE

Navigating PDA & Autism in the USA—A Family Resource Guide

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**BRIGHTPATH
PUBLISHING**

Unlocking Potential, Empowering Futures

Support Guide for Individuals Residing in the United States

A new PDA or Autism diagnosis can bring a flood of questions and pressure. *Where do I even begin to find help in the US?* This Practical Parent's Guide Resource Guide is your answer to 'step one.' It's a carefully compiled list of resources to help you begin navigating this journey.

Inside, you'll find resources to explore: understanding the diagnosis process, accessing different therapies, and untangling financial support programs like CHIP and Medicaid. We also point you towards resources for school advocacy (IEPs and 504s), alternative schooling options, strategies for managing meltdowns, and support for your family's well-being. And yes, even resources to help you start fostering your child's independence.

This guide is designed to be your launchpad – a list of key resources to get you started. Our book, "*The Practical Parent's Guide to PDA and Autism*," is where we truly unpack each of these areas. The book provides in-depth strategies, personal stories, and expert advice to guide you every step of the way. Use this guide to begin, and know that the book is there for deeper support.

ADVOCACY

Kids Waivers

<https://www.kidswaivers.org>

An informational resource that helps families navigate Medicaid waivers and related programs for children with disabilities across the United States.



National Alliance on Mental Illness (NAMI)

<https://www.nami.org>

NAMI offers support groups and educational programs for families of individuals with mental health conditions, including those with PDA.

National Association of Disability Representatives

<https://www.nadr.org>

A professional organization that supports advocates and representatives dedicated to assisting individuals in obtaining Social Security Disability benefits.

National Disabilities Rights Network

<https://www.ndrn.org>

A nonprofit organization dedicated to advocating for the civil and human rights of individuals with disabilities through legal advocacy, education, and support.

NEXT for AUTISM

<https://nextforautism.org/>

Partners with and funds organizations to expand access to programs and services for the autism community.

PDA North America

<https://pdanorthamerica.com>

PDA North America offers resources for families dealing with emotional regulation issues in children with PDA, including therapy options.

The Arc

<https://thearc.org>

A national organization advocating for individuals with intellectual and developmental disabilities, providing guidance on diagnosis, therapy options, and insurance.

The Autism Society

<https://autismsociety.org/>



The oldest and largest grassroots autism organization in the U.S., offering advocacy, education, services, and support to autistic individuals, their families, and professionals.

The Autistic Self Advocacy Network (ASAN)

<https://autisticadvocacy.org/>

ASAN provides support, community, and public policy advocacy for people on the autism spectrum, empowering self-advocacy.

The PDA Society

<https://www.pdasociety.org.uk>

Provides extensive resources, information, and support for individuals, families, and professionals dealing with Pathological Demand Avoidance.

Understood.org

<https://www.understood.org>

A nonprofit organization dedicated to providing resources, tools, and support to individuals with learning and thinking differences and their families to help them thrive at home, in school, and at work.

Wrightslaw

<https://www.wrightslaw.com>

A leading resource for parents, educators, and attorneys dealing with special education law and advocacy, providing detailed information on IDEA, 504 Plans, and navigating the special education system.

CHARTER SCHOOLS

Connections Academy

<https://www.connectionsacademy.com>

A tuition-free online public school that offers flexible, high-quality K-12 education tailored to students' individual needs, supported by certified teachers and a comprehensive curriculum.



K12 Online Schools

<https://www.k12.com>

Provides flexible, tuition-free online education programs for students in kindergarten through 12th grade, offering personalized learning experiences supported by certified teachers.

EMOTIONAL SUPPORT AND MENTAL HEALTH RESOURCES

PARENTS AND CAREGIVERS

Family Voices

<https://familyvoices.org>

Offers peer support groups, webinars, and counseling services, helping parents navigate the emotional stress of caregiving.

Parent to Parent USA

<https://www.p2pusa.org>

Connects families raising children with disabilities to trained parent mentors who provide emotional support and practical advice.

CHILDREN

Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)

<https://chadd.org>

Provides emotional support services, coping skills training, and peer mentorship programs for children and adolescents with ADHD.

Therapy for Children with PDA

<https://pdanorthamerica.com>

PDA North America offers resources for families dealing with emotional regulation issues in children with PDA, including therapy options.



The Sibling Support Project

<https://siblingsupport.org>

Provides peer support, recreational activities, and mental health resources, including "Sibshops" for siblings of children with disabilities.

EMPLOYMENT

Organization for Autism Research (OAR)

<https://researchautism.org/product/a-guide-for-transition-to-adulthood/>

OAR provides "Life Journey Through Autism: A Guide for Transition to Adulthood," offering comprehensive resources on education, employment, and independent living for young adults with autism.

Project SEARCH

<https://www.projectsearch.us/>

A transition program helping young adults with intellectual and developmental disabilities gain work experience through internships, preparing them for competitive employment.

The Arc's Center for Future Planning

<https://futureplanning.thearc.org/>

Provides resources to help families create comprehensive future care plans, covering legal, financial, and daily care considerations.

Think College Search

<https://thinkcollege.net/college-search>

Think College offers a search tool to help individuals with intellectual disabilities find inclusive higher education programs across the U.S.

HOME-BASED SUPPORT

Easterseals

<https://www.easterseals.com>



Offers Early Intervention services, in-home therapy, respite care, and assistive technology for children with autism and ADHD.

Family Voices

<https://familyvoices.org>

A national network providing peer support, emotional counseling, and resources for families of children with special healthcare needs.

Medicaid Home and Community-Based Services (HCBS)

Waivers

<https://www.medicaid.gov/medicaid/home-community-based-services/index.html>

Provides Medicaid funding for home-based care services, including personal care, respite care, and therapeutic services for children with disabilities.

LEGAL

Council of Parents Attorneys and Advocates (COPAA)

<https://www.copaa.org>

A nonprofit organization dedicated to protecting and enforcing the legal and civil rights of students with disabilities and their families through advocacy, education, and legal representation.

Disability Rights Education & Defense Fund

<https://dredf.org>

A leading civil rights law and policy center dedicated to advancing the rights of people with disabilities through advocacy, legal support, and education.



Home School Legal Defense Association

<https://hsllda.org>

A nonprofit organization that provides legal support, advocacy, and resources to protect and advance the rights of homeschooling families.

National Academy of Elder Law Attorneys (NAELA)

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

Provides resources for families planning long-term care and financial security for individuals including children with disabilities.

National Association of Disability Representatives

<https://www.nadr.org>

A professional organization that supports advocates and representatives dedicated to assisting individuals in obtaining Social Security Disability benefits.

National Disabilities Rights Network

<https://www.ndrn.org>

A nonprofit organization dedicated to advocating for the civil and human rights of individuals with disabilities through legal advocacy, education, and support.

Wrightslaw

<https://www.wrightslaw.com>

A leading resource for parents, educators, and attorneys dealing with special education law and advocacy, providing detailed information on IDEA, 504 Plans, and navigating the special education system.

MEDICAL DIAGNOSIS AND INSURANCE

ADOS-2 (Autism Diagnostic Observation Schedule)

<https://www.wpspublish.com/ados-2-autism-diagnostic-observation-schedule-second-edition>



A standardized assessment tool used by professionals to diagnose autism spectrum disorder through structured observations of social and communication behaviors.

American Psychological Association (APA)

<https://www.apa.org>

Offers information on finding licensed psychologists or counselors and resources on the benefits of therapy.

Autism Diagnosis Group (ADG)

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

ADG offers fast, accessible online autism evaluations, reducing long wait times. They work with major insurance providers and provide ongoing support by connecting families with therapists and resources.

Children's Health Insurance Program (CHIP)

<https://www.insurekidsnow.gov>

Offers health coverage to children in families that earn too much for Medicaid but cannot afford private insurance, covering diagnostic services, mental health care, and treatment for autism and ADHD.

Early and Periodic Screening, Diagnostic, and Treatment (EPSDT)

<https://www.medicaid.gov/medicaid/benefits/early-and-periodic-screening-diagnostic-and-treatment/index.html>

A Medicaid benefit ensuring children under 21 receive appropriate preventive, dental, mental health, and developmental services, including diagnosis and treatment for autism and ADHD.

Institute of Functional Medicine

<https://www.ifm.org>

IFM offers education and resources focusing on personalized, patient-centered therapies that address underlying causes of disease.



M-CHAT Modified Checklist for Autism in Toddlers

<https://www.mchatscreen.com>

A widely used screening tool designed to identify signs of autism spectrum disorder in toddlers aged 16-30 months.

Medicaid

<https://www.medicaid.gov>

Provides health coverage to low-income individuals, including children with disabilities, covering diagnostic and treatment costs for autism, ADHD, and other developmental disorders.

National Autism Center (NAC)

<https://www.nationalautismcenter.org>

Offers evidence-based practices for autism treatment and guidance on accessing diagnostic services, therapies, and educational support.

PDA Affirming Providers (PDA North America)

https://docs.google.com/document/d/18mD3towwOpu4bA7lOecVP4p2pAZrI71Pe_qs7Ah80yA/edit?tab=t.0

A curated directory of professionals and organizations that support and work with individuals and families navigating Pathological Demand Avoidance (PDA) in a respectful and affirming manner.

Psychology Today

<https://www.psychologytoday.com>

Features a comprehensive directory of therapists, counselors, and support groups to help you find qualified professionals in your area.

PX Docs

<https://pxdocs.com/>

Connects families with pediatric-focused chiropractors, offering natural approaches to support children's health, including those with neurodevelopmental disorders.



Sensory Profile 2

<https://www.pearsonassessments.com/store/usassessments/en/Store/Professional-Assessments/Motor-Sensory/Sensory-Profile-2/>

A standardized assessment tool designed to evaluate sensory processing patterns in children and their impact on functional participation in everyday life.

Social Responsiveness Scale (SRS-2)

<https://www.wpspublish.com/srs-2-social-responsiveness-scale-second-edition>

A standardized assessment tool that measures social impairments associated with autism spectrum disorder and other conditions across a wide range of ages.

TEFRA/Katie Beckett Waivers

<https://dhcf.dc.gov/katiebeckett>

TEFRA/Katie Beckett waivers allow children with disabilities or complex medical needs to qualify for Medicaid coverage based on their own income and assets, regardless of parental income, enabling access to critical care services.

The Upledger Institute

<https://www.upledger.com>

A healthcare organization specializing in Craniosacral Therapy and related holistic therapies, offering training programs and treatment services worldwide.

Vineland Adaptive Behavior Scales

<https://www.pearsonassessments.com/store/usassessments/en/Store/Professional-Assessments/Behavior/Vineland-Adaptive-Behavior-Scales-%7C-Third-Edition/p/100001622.html>

Is a standardized assessment tool used to measure adaptive behavior in



individuals with developmental, intellectual, and other disabilities, focusing on their ability to perform daily activities.

ONLINE LEARNING

Khan Academy

<https://www.khanacademy.org>

Known for its instructional videos and practice exercises, this platform covers various subjects and has children revisit concepts at their leisure.

MiAcademy

<https://miacademy.co/#/>

An accredited curricula for K-12 students, allowing learners to progress through lessons at their own speed.

Outschool

<https://outschool.com>

With live classes on unique topics, your child can explore interests ranging from art to coding.

Power Homeschool

<https://www.powerhomeschool.org>

A K-12 program with interactive video lessons, helping children to explore topics visually and at their own pace.

Time4Learning.com

<https://www.time4learning.com>

This platform uses multimedia lessons to make subjects engaging and interactive.



RESPIRE CARE PROVIDERS

ARCH National Respite Network

<https://archrespite.org>

Offers a nationwide network of respite care providers, providing short-term relief for caregivers of individuals with disabilities.

RELAXATION TOOLS

Calm App

<https://www.calm.com>

Offers soothing music and guided meditations to help calm and distract children during stressful times.

Headspace App

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

A mindfulness and meditation tool designed to help users reduce stress, improve focus, and enhance overall well-being through guided meditations and wellness resources.

RESOURCE GROUPS

Autism Care Today

<https://act-today.org>

A nonprofit organization dedicated to providing financial assistance and support to families to help children with autism access care and critical services.

Care.com

<https://www.care.com>

An online platform to find caregivers, tutors, and other support services to help lighten your load.



Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)

<https://chadd.org>

Provides resources and support that can be applicable to siblings of children with PDA.

Sibling Support Project

<https://siblingsupport.org>

Offers online support groups and resources like "Sibshops" for siblings of children with special needs.

The Mighty

<https://themighty.com>

An online community where people share stories and experiences related to mental health, disability, and chronic illness.

Therapist Aid

<https://www.therapistaid.com>

Offers free resources including worksheets, activities, and information on various types of therapy for parents and therapists.

United Healthcare Children's Foundation

<https://www.uhccf.org>

Provides medical grants to help families cover the costs of children's healthcare treatments, services, and equipment not fully covered by insurance.

SCHOOL SUPPORT AND EDUCATIONAL RESOURCES

Department of Education or the National Charter School Resource Center

<https://charterschoolcenter.ed.gov>

The National Charter School Resource Center, supported by the



Department of Education, provides high-quality resources, tools, and guidance to strengthen charter schools and support their success across the United States.

Free Appropriate Public Education (FAPE)

<https://www.ed.gov/laws-and-policy/civil-rights-laws/disability-discrimination/disability-discrimination-key-issues/disability-discrimination-providing-free-appropriate-public-education-fape>

Ensures that all students with disabilities are entitled to access specialized educational services at no cost, tailored to their individual needs, under federal civil rights laws.

Home School Legal Defense Association

<https://hsllda.org>

A nonprofit organization that provides legal support, advocacy, and resources to protect and advance the rights of homeschooling families.

Individuals with Disabilities Education Act (IDEA)

<https://sites.ed.gov/idea>

Mandates that public schools provide free and appropriate education to eligible children with disabilities, including autism and ADHD, through Individualized Education Plans (IEPs).

National Professional Development Center on Autism Spectrum Disorder

<https://autismpdc.fpg.unc.edu>

Provides evidence-based practices, training, and resources to improve outcomes for individuals with autism spectrum disorder.

Practical Management Strategy – P.A.N.D.A.

<https://uk.jkp.com/products/collaborative-approaches-to-learning-for-pupils-with-pda>

Offers educators practical tools to support pupils with Pathological Demand Avoidance through understanding, flexibility, and collaboration.



The National Alliance for Public Charter School

<https://publiccharters.org>

A nonprofit organization dedicated to advancing the public charter school movement by advocating for high-quality educational opportunities for all students.

U.S. Department of Education's Summary of State Laws

<https://www.ed.gov/teaching-and-administration/safe-learning-environments/school-safety-and-security/school-climate-and-student-discipline/summary-of-seclusion-and-restraint-statutes-regulations-policies-and-guidance-by-state-and-territories>

Provides a comprehensive overview of seclusion and restraint statutes, regulations, policies, and guidance across states and territories to promote safe and supportive learning environments.

Vanderbilt University's Functional Behavior Plan

<https://iris.peabody.vanderbilt.edu>

A framework designed to help educators and caregivers address challenging behaviors in students by identifying their underlying causes and implementing targeted, evidence-based strategies.

504 Plans

<https://www.ed.gov/laws-and-policy/individuals-disabilities/section-504>

Ensures that students with disabilities receive accommodations enabling them to participate fully in school activities.

SOCIAL SECURITY DISABILITY BENEFITS AND MEDICAID

Children's Health Insurance Program (CHIP)

<https://www.insurekidsnow.gov>

Offers health coverage to children in families that earn too much for



Medicaid but cannot afford private insurance, covering diagnostic services, mental health care, and treatment for autism and ADHD.

Disability Benefits Center

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

Provides guidance on applying for Social Security Disability Insurance (SSDI) and SSI, helping families navigate the application process.

Early and Periodic Screening, Diagnostic, and Treatment (EPSDT)

<https://www.medicaid.gov/medicaid/benefits/early-and-periodic-screening-diagnostic-and-treatment/index.html>

A Medicaid benefit ensuring children under 21 receive appropriate preventive, dental, mental health, and developmental services, including diagnosis and treatment for autism and ADHD.

Medicaid

<https://www.medicaid.gov>

Provides health coverage to low-income individuals, including children with disabilities, covering diagnostic and treatment costs for autism, ADHD, and other developmental disorders.

National Disability Institute (NDI)

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

Offers financial education and counseling for individuals with disabilities, including resources for SSI, SSDI, and other financial programs.

Social Security Administration (SSA)

<https://www.ssa.gov/ssi/text-child-ussi.htm>, www.ssa.gov/applyforbenefits

Administers the Supplemental Security Income (SSI) program, providing financial assistance to individuals with disabilities.

Social Security Administration (SSA) Child Disability Report

<https://secure.ssa.gov/apps6z/i3820/main.html>

An online tool that helps parents or guardians provide detailed information



about a child's medical conditions to determine eligibility for Supplemental Security Income (SSI) benefits.

SPECIAL NEEDS TRUSTS AND FINANCIAL SUPPORT

Academy of Special Needs Planners (ASNP)

<https://specialneedsanswers.com>

Provides resources and guidance for families planning the financial future of a loved one with a disability, assisting with setting up Special Needs Trusts.

National Academy of Elder Law Attorneys (NAELA)

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

Provides resources for families planning long-term care and financial security for individuals including children with disabilities.

Special Needs Alliance

<https://www.specialneedsalliance.org>

A national network of attorneys specializing in disability law, offering legal advice on setting up special needs trusts and managing benefits.

TEACHING TOOLS

Carol Gray Social Stories

<https://carolgraysocialstories.com>

Offers personalized stories that describe specific social situations and appropriate responses, helping children with PDA navigate interactions.

Choiceworks App

<https://apps.apple.com/us/app/choiceworks/id486210964>

An app designed to help children with autism and other special needs by providing visual supports for daily routines, emotional regulation, and promoting independence.



Everyday Speech

<https://www.everydayspeech.com>

Offers a social skills curriculum with videos, activities, and worksheets to help children practice and improve their social skills.

Goally

<https://getgoally.com>

A device that assists children with transitions by providing visual and auditory prompts for upcoming activities.

GoZen! Program

<https://gozen.com>

Offers techniques to help children understand and manage their emotions, including methods for validating feelings.

Happy Hooligans Reward Charts

<https://happyhooligans.ca>

Offers printable reward charts customizable to fit your child's routine and reinforce positive behavior.

MindUP Program

<https://mindup.org>

Provides resources for parents and teachers to help children develop resilience through mindfulness and positive psychology.

The Feelings Wheel by Dr. Gloria Willcox

<https://feelingswheel.com>

A visual tool that helps children identify and articulate their emotions, enhancing expressive language skills.

The Incredible 5-Point Scale

<https://www.5pointscale.com>

Helps children understand and manage their social and emotional responses by breaking them down into five levels.



Zones of Regulation

<https://www.zonesofregulation.com>

Provides tools and strategies to help children recognize and manage their emotions.

THERAPY

Acceptance and Commitment Therapy (ACT)

The Association for Contextual Behavioral Science (ACBS)

<https://contextualscience.org>

A worldwide community dedicated to advancing evidence-based practices, such as Acceptance and Commitment Therapy (ACT), through research, education, and clinical application.

American Psychological Association

<https://www.apa.org>

A leading scientific and professional organization in psychology, dedicated to advancing psychological research, education, and practice to improve mental health and well-being

Collaborative and Proactive Solutions (CPS)

<https://drrossgreene.com/about-cps.htm>

An evidence-based approach developed by Dr. Ross Greene that focuses on resolving challenging behavior in children through collaboration, empathy, and skill-building.

Dialectical Behavior Therapy (DBT)

The National Education Alliance for Borderline Personality Disorder (NEABPD)

<https://www.borderlinepersonalitydisorder.org>

A non-profit organization dedicated to raising awareness, providing education, and promoting research on borderline personality disorder to improve treatment and support for individuals and families.

Emotional Regulation Therapy

The National Institute for the Clinical Application of Behavioral Medicine

<https://www.nicabm.com>

Online training and resources for healthcare professionals to integrate mindfulness, neuroscience, and behavioral medicine into clinical practice.

Floortime

<https://www.icdl.com>

A developmental approach designed to support children with autism and other developmental challenges by building social, emotional, and communication skills through interactive, play-based engagement.

Modified Cognitive Behavioral Therapy (CBT)

Association for Behavioral and Cognitive Therapies (ABCT)

www.abct.org

A multidisciplinary organization committed to the advancement of evidence-based behavioral and cognitive therapies through research, education, and clinical practice.

Occupational Therapy

The American Occupational Therapy Association (AOTA)

<https://www.aota.org>

A national professional association representing occupational therapy practitioners and students, dedicated to promoting the profession through advocacy, education, and research.

Parent Training

The PDA Society

<https://www.pdasociety.org.uk/resources/resource-category/webinars-and-videos/>

Online course for parents and caregivers on managing PDA behaviors, giving you everything necessary to assist your child with confidence and skill.



Play Therapy

The Association for Play Therapy

www.a4pt.org, <https://autplaytherapy.com>

A professional organization dedicated to advancing play therapy through education, research, and support for practitioners to enhance the mental health and well-being of children and families.

Sensory Integration Therapy

STAR Institute for Sensory Processing

<https://sensoryhealth.org>

A therapeutic approach designed to help individuals with sensory processing challenges improve their ability to respond to sensory stimuli in a more adaptive way.

Speech Therapy

American Speech-Language-Hearing Association (ASHA)

<https://www.asha.org>

A professional organization dedicated to advancing speech, language, and hearing services through advocacy, education, and certification for speech-language pathologists, audiologists, and related professionals.

TIME MANAGEMENT

First Then Visual Schedule App

<https://itunes.apple.com/us/app/first-then-visual-schedule/id355527801?mt=8>

A customizable scheduling tool that helps children with special needs manage their day.

SchKIDules

<https://www.schkidules.com>

Uses magnets or a digital format to give children control over their daily routines.



Time Timer

<https://www.timetimer.com>

A simple visual timer showing time passing in an easy-to-understand way, useful for managing transitions.

WEALTH MANAGERS

A Special Needs Plan

<https://aspecialneedsplan.com/>

A nationwide advisory firm dedicated to assisting families in planning for the future care and financial well-being of their loved ones with special needs.

Northwestern Mutual

<https://www.northwesternmutual.com/financial-planning/special-needs-planning/>

Provides specialized financial planning services, including estate planning and special needs trusts, to help families secure the future of their loved ones with special needs.

Oak Wealth Advisors

<https://oakwealth.com/>

Provides experienced and objective planning advice and investment management services, specializing in assisting families with loved ones who have disabilities.

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A Note on International Resources

Parenting is a universal journey, and we recognize that our readers hail from all around the world. We're committed to supporting you with resources as comprehensive as those provided in the United States guide at the end of this book. While our U.S. resources are extensive, we strive to offer similar support internationally. If you reside in Belgium, Brazil, Canada, France, Germany, India, Italy, Japan, Latin America, Mexico, Portugal, Singapore, South Korea, Spain, Taiwan, the Netherlands, or the United Kingdom, we invite you to visit our website at practicalparentsguide.com. There, you can download our International Resource Guide for detailed support tailored to your region.

