

Dear Pediatric Screening Families:

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Needs Concerns	Education/Resource
Common syndromes and Genetic conditions associated with intellectual disabilities	<p>Down syndrome</p> <ul style="list-style-type: none"> <input type="checkbox"/> Global Down Syndrome Foundation- https://www.globaldownsyndrome.org/ Dedicated to significantly improving the lives of people with Down syndrome through research, medical care, education and advocacy <input type="checkbox"/> National Association for Down Syndrome- (https://www.nads.org/) Supports all persons with Down syndrome in achieving their full potential. Seeks to help families, educate the public, address social issues and challenges, and facilitate active participation <input type="checkbox"/> National Down Syndrome Society- (https://www.ndss.org/) Seeks to increase awareness and acceptance of those with Down syndrome <input type="checkbox"/> Healthychildren.org-https://www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/Children-with-Down-Syndrome-Health-Care-Information-for-Families.aspx Healthcare information for Families of Children with Down syndrome <input type="checkbox"/> Parent Center Hub: https://www.parentcenterhub.org/downsyndrome/#parents Resources to support parents and caregivers of children with disabilities <input type="checkbox"/> Down syndrome Clinics: https://www.ndsccenter.org/programs-resources/health-care/down-syndrome-clinics/ Local Down Syndrome clinics <p>Fragile X syndrome (FXS)</p> <ul style="list-style-type: none"> <input type="checkbox"/> National Fragile X Foundation: https://fragilex.org/ Up to date information on Fragile X <input type="checkbox"/> Fragile X Support Groups: https://fragilex.org/living-with-fragile-x/community-support/ Support groups for parents of children with Fragile X <p>Prader Willi syndrome (PWS)</p> <ul style="list-style-type: none"> <input type="checkbox"/> PWS Support groups: https://www.pwsausa.org/ Support groups for parents of children with Prader Willi syndrome <p>Resources for other conditions</p> <ul style="list-style-type: none"> <input type="checkbox"/> Fetal Alcohol Spectrum Disorders: https://www.aap.org/en/patient-care/fetal-alcohol-spectrum-disorders/ <input type="checkbox"/> International 22q11.2: https://22q.org/

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Vaccine Awareness	<ul style="list-style-type: none"> <input type="checkbox"/> Kids Health: https://kidshealth.org/en/parents/fact-myth-immunizations.html?ref=search Vaccine information, facts, and myths <input type="checkbox"/> CDC: https://www.cdc.gov/vaccines/schedules/hcp/imz/child-adolescent.html CDC recommended childhood vaccines <input type="checkbox"/> WHO: https://www.who.int/immunization/policy/Immunization_routine_table2.pdf WHO recommended childhood vaccines
Vision	<ul style="list-style-type: none"> <input type="checkbox"/> Kids Health Your: https://kidshealth.org/en/parents/vision.html Information on your child's vision <input type="checkbox"/> American Optometric Association: https://www.aoa.org/healthy-eyes/eye-health-for-life/preschool-vision?sso=y Vision for Preschoolers (2-5yrs) <input type="checkbox"/> Kids Health: https://kidshealth.org/en/parents/strabismus.html Strabismus and why it needs to be detected and treated <input type="checkbox"/> Parent Center Hub: https://www.parentcenterhub.org/visualimpairment/ Center for parent information and resources <input type="checkbox"/> WHO: https://www.who.int/news-room/fact-sheets/detail/blindness-and-visual-impairment Blindness and vision impairment resources <input type="checkbox"/> Braille Institute: https://brailleinstitute.org/ Free programs and services for those with low vision to no vision
Hearing	<ul style="list-style-type: none"> <input type="checkbox"/> CDC: https://www.cdc.gov/ncbddd/hearingloss/parentsguide/hearingloss/intervention-support.html Understanding hearing loss <input type="checkbox"/> John Tracy Clinic: https://www.jtc.org/ Diagnostic and education center for young children <input type="checkbox"/> Hearing Loss Association of America: https://www.hearingloss.org/ National leader in representing hearing loss
Oral Hygiene	<ul style="list-style-type: none"> <input type="checkbox"/> Autism Speaks: https://www.autismspeaks.org/tool-kit/dental-tool-kit Dental toolkit <input type="checkbox"/> Autism Speaks: https://www.autismspeaks.org/tool-kit-excerpt/preparing-dental-visit Preparing for dental visit <input type="checkbox"/> CDC: https://www.cdc.gov/oralhealth/basics/childrens-oral-health/index.html Tips for at home dental care

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Developmental Delay	<ul style="list-style-type: none"> <input type="checkbox"/> The Importance of Early Intervention: https://ectacenter.org/~pdfs/pubs/importanceofearlyintervention.pdf Importance of acting early <input type="checkbox"/> CDC: https://www.cdc.gov/ncbddd/childdevelopment/freematerials.html CDC developmental fact sheets <input type="checkbox"/> WHO: https://www.who.int/publications/i/item/97892400020986 Improving early childhood development <input type="checkbox"/> Children's Hospital of Philadelphia: https://www.chop.edu/conditions-diseases/language-disorders-children What is a language disorder? <input type="checkbox"/> American Speech-Language-Hearing Association: https://www.asha.org/public/who-are-speech-language-pathologists/ What is Speech/Language Therapy? <input type="checkbox"/> Kids Health: https://kidshealth.org/en/parents/occupational-therapy.html What is Occupational Therapy? <input type="checkbox"/> Kids Health: https://kidshealth.org/en/parents/phys-therapy.html What is Physical Therapy? <input type="checkbox"/> Healthy Children: https://www.healthychildren.org/English/family-life/health-management/pediatric-specialists/Pages/What-is-a-Developmental-Behavioral-Pediatrician.aspx#:~:text=Developmental%2Dbehavioral%20pediatricians%20evaluate%2C%20counsel,other%20school%2Drelated%20learning%20problems What is a developmental pediatrician? <input type="checkbox"/> Parent to Parent USA: https://www.p2pusa.org/parents/ Parent support <input type="checkbox"/> Parent to Parent USA: https://www.p2pusa.org/parents/ Parental Stress <input type="checkbox"/> Bright Futures: https://www.brightfutures.org/bf2/pdf/pdf/EC.pdf Bright Futures guide for parents on toddler development <input type="checkbox"/> Autism Speaks: https://www.autismspeaks.org/sensory-issues Sensory issues <p>Book recommendations for children with sensory issues:</p> <ul style="list-style-type: none"> <input type="checkbox"/> <i>The Out of Sync Child</i> by Carol Kranowitz <input type="checkbox"/> <i>Raising a Sensory Smart Child</i> by Lindsay Biel <p>Book recommendations for development in children with Down syndrome:</p> <ul style="list-style-type: none"> <input type="checkbox"/> <i>Early Communication Skills for Children with Down Syndrome: A Guide for Parents and Professionals</i> by Libby Kumin PhD <input type="checkbox"/> <i>Fine Motor Skills for Children with Down Syndrome: A Guide for Parents and Professionals</i> by Maryanne Bruni BScOT <input type="checkbox"/> <i>Gross Motor Skills for Children with Down Syndrome: A Guide for Parents and Professionals</i> by Patricia Winters PT

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Behavioral/Developmental Issues	<p><input type="checkbox"/> CDC: https://www.cdc.gov/ncbddd/childdevelopment/positiveparenting/index.html Positive parenting strategies</p> <p><input type="checkbox"/> Specifics from Parent-Child Interaction Therapy (PCIT) About PCIT: https://pcit.ucdavis.edu/about-pcit/ Why praise: https://pcit.ucdavis.edu/why-praise/ PRIDE skills for parent-child relationship enhancement: https://pcit.ucdavis.edu/forms/cdi-forms/</p> <p><input type="checkbox"/> The Incredible Years https://incredibleyears.com/ Series of interlocking, evidence-based programs for parents, children, and teachers. Preventing and treat young children's behavior problems and promote their social, emotional and academic competence</p> <p>General Behavior Books:</p> <p><input type="checkbox"/> <i>The whole-Brain Child: 12 Revolutionary Strategies to Nurture your Child's Developing Mind</i> by Daniel J. Siegel</p> <p><input type="checkbox"/> <i>SOS Help for Parents: A Practical Guide for Handling Common Everyday Behavior Problems</i> by Lynn Clark</p> <p><input type="checkbox"/> <i>1, 2, 3 Magic, Effective Discipline for Children 2-12</i> by Thomas Phelan</p> <p>Autism</p> <p><input type="checkbox"/> Autism Speaks: https://www.autismspeaks.org/autism-speaks-tool-kits Autism Speaks is an organization that promotes solutions, across the spectrum and throughout the life span, for individuals with autism and their families</p> <p><input type="checkbox"/> Autism Speaks: https://www.autismspeaks.org/applied-behavior-analysis Information on Applied Behavior Analysis (ABA)</p> <p>ADHD</p> <p><input type="checkbox"/> CHADD: https://chadd.org/ Children and Adults with Attention-Deficit/Hyperactivity Disorder</p> <p><input type="checkbox"/> The Children's Hospital of Philadelphia: https://media.chop.edu/data/files/pdfs/pfe/strategies-teaching-children-with-adhd.pdf Parent guide for Children with ADHD</p> <p><input type="checkbox"/> Healthy Children: https://www.healthychildren.org/English/health-issues/conditions/adhd/Pages/Behavior-Therapy-Parent-Training.aspx Overview of behavior therapy for ADHD</p> <p>ADHD Books:</p> <p><input type="checkbox"/> <i>Taking Charge of ADHD</i> by Russell Barkley</p> <p><input type="checkbox"/> <i>Smart But Scattered</i> by Dawson and Guare</p>

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Needs Concerns	Education/Resource
Mental Health	<p>Anxiety</p> <ul style="list-style-type: none"> <input type="checkbox"/> Anxiety & Depression Association of America: https://adaa.org/find-help/by-demographics/children/children-teens Anxiety in children and their treatment <input type="checkbox"/> Worry Wise Kids: http://worrywisekids.org/ Anxiety Red flags, causes, types, treatment <input type="checkbox"/> National Institute of Mental Health: https://www.nimh.nih.gov/health/publications/children-and-mental-health When to seek help? <input type="checkbox"/> Substance Abuse and Mental Health Services Administration (SAMHSA): https://findtreatment.samhsa.gov/ treatment service locator <p>Depression</p> <ul style="list-style-type: none"> <input type="checkbox"/> CDC: https://www.cdc.gov/childrensmentalhealth/depression.html Depression in children <input type="checkbox"/> Kids Health: https://kidshealth.org/en/parents/understanding-depression.html Childhood depression, what parents need to know <p>Anxiety Books</p> <ul style="list-style-type: none"> <input type="checkbox"/> <i>Freeing Your Child from Anxiety</i> by Tamar Chansky
Education	<p>Education Rights and Laws</p> <ul style="list-style-type: none"> <input type="checkbox"/> Ed.gov: https://sites.ed.gov/idea/ Individuals with Disabilities Education Act (IDEA). According to Part C of IDEA, families and children with DD/ID younger than age 3 can receive early intervention services. Individuals from ages 3 through 21 receive special education and related services under IDEA Part B. Assistive Technology Act provides assistive technology to individuals with disabilities so they can fully participate in education, employment and daily activities. Family Educational Rights and Privacy Act is a law that protects the privacy of a student's school records. These rights are transferred to the student when they reach the age of 18 or attend school beyond the high school level. <input type="checkbox"/> Kids Health: https://kidshealth.org/en/parents/iep.html Individualized Education Plan (IEP) <input type="checkbox"/> Kids Health: https://kidshealth.org/en/parents/504-plans.html 504 Plan <input type="checkbox"/> Autism Speaks: https://www.autismspeaks.org/autism-school-your-childs-rights Autism and educational rights <input type="checkbox"/> TASK: https://taskca.org/ Support and education about special education systems and processes <input type="checkbox"/> Parent Center Hub: https://www.parentcenterhub.org/find-your-center/ Parent Resource Centers by state

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Food Assistance	<ul style="list-style-type: none"> <input type="checkbox"/> WIC: https://www.fns.usda.gov/wic/toll-free-numbers-wic-state-agencies Special Supplemental Nutrition Program for Women, Infants and Children (WIC)- phone # by state Supplemental <input type="checkbox"/> SNAP: https://www.fns.usda.gov/snap/state-directory Nutrition Assistance Program (SNAP) national- how to apply by state <input type="checkbox"/> School Lunch Programs: https://www.cde.ca.gov/ls/nu/sn/eligmaterials.asp National school lunch/breakfast program, special milk program, state meal program – application info <input type="checkbox"/> No Kid Hungry: https://www.nokidhungry.org/ Free meal finder
Housing assistance	<ul style="list-style-type: none"> <input type="checkbox"/> 1 Degree: https://www.1degree.org/ Helps you find and access community resources including affordable housing, homeless support, temporary housing <input type="checkbox"/> US Government Benefits for Housing: https://www.benefits.gov/news/article/356 Options for housing assistance <input type="checkbox"/> US Government Benefits for Disability: https://www.benefits.gov/benefit/5892 Assistance for those with adult family member with disability
Utilities assistance	<ul style="list-style-type: none"> <input type="checkbox"/> US Offices of Community Services: https://www.acf.hhs.gov/ocs/low-income-home-energy-assistance-program-liheap Low Income Home Energy Assistance Program (LIHEAP) <input type="checkbox"/> US Home Energy Assistance: https://hhs-acf.maps.arcgis.com/apps/opsdashboard/index.html#/683ba3b0c2064498a4a60fc04644a1ea Find your local energy assistance provider
Toxin exposure (Lead, smoke)	<ul style="list-style-type: none"> <input type="checkbox"/> Healthy Children: https://www.healthychildren.org/English/safety-prevention/all-around/Pages/Blood-Lead-Levels-in-Children-What-Parents-Need-to-Know.aspx Blood lead levels; what parents need to know <input type="checkbox"/> Healthy Children: https://www.healthychildren.org/English/health-issues/conditions/tobacco/Pages/Dangers-of-Secondhand-Smoke.aspx Dangers of secondhand smoke <p>Poison Control Number: (800) 222-1222</p>

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Health Insurance	<ul style="list-style-type: none"> <input type="checkbox"/> Healthcare.gov: https://www.healthcare.gov/medicaid-chip/childrens-health-insurance-program/ Medicaid provides free or low-cost health coverage to some low-income families and people with disabilities. Children's Health Insurance Program (CHIP) works through Medicaid and other separate CHIP programs to provides low-cost health coverage to children in families that do not qualify for Medicaid based on income. For more information about eligibility and rights for state expression of Medicaid/CHIP insurance for all children, and for those with special needs <input type="checkbox"/> Kids Health: https://kidshealth.org/en/parents/find-care.html How to find affordable health care <input type="checkbox"/> National Conference of State Legislatures: https://www.ncsl.org/research/health/autism-and-insurance-coverage-state-laws.aspx Insurance coverage laws for autism in different states
Bullying	<ul style="list-style-type: none"> <input type="checkbox"/> Autism Speaks: https://www.autismspeaks.org/combating-bullying Resources on combating bullying <input type="checkbox"/> Stop Bullying: https://www.stopbullying.gov/ Identify bullying and safely standing up to it
Safety	<p>Wandering/ Elopement</p> <ul style="list-style-type: none"> <input type="checkbox"/> Autism Speaks: https://www.autismspeaks.org/safety-products-and-services Things to consider when creating a multifaceted safety plan <input type="checkbox"/> Autism Speaks: https://www.autismspeaks.org/wandering-prevention-resources Wandering prevention resources <p>Self-Injury</p> <p>Addressing & 5 common reasons for self-injury: https://www.autismspeaks.org/expert-opinion/physical-discipline-autism-parent-asks-guidance</p> <p>Causes and interventions for self-injury in autism: https://www.autism.org/causes-and-interventions-for-self-injury-in-autism/</p> <p>Transportation Safety</p> <ul style="list-style-type: none"> <input type="checkbox"/> More information about child safety seats for children with special health care needs 1-800-755-0912 <input type="checkbox"/> Safe Kids: https://www.safekids.org/events Car seat checkups in your area 866-732-8243 <p>Medication Safety</p> <ul style="list-style-type: none"> <input type="checkbox"/> Healthy Children: https://www.healthychildren.org/English/safety-prevention/at-home/medication-safety/Pages/Medication-Safety-Tips.aspx Medication safety tips for families

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Nutrition/Gastrointestinal Issues	<p>Constipation</p> <ul style="list-style-type: none"> <input type="checkbox"/> Healthy Children: https://www.healthychildren.org/English/health-issues/conditions/abdominal/Pages/Constipation.aspx More information about constipation in children <input type="checkbox"/> Kids Health: https://kidshealth.org/en/parents/constipation.html What parents need to know about causes of constipation and how to prevent it <p>Picky eaters</p> <ul style="list-style-type: none"> <input type="checkbox"/> CDC: https://www.cdc.gov/nutrition/infantandtoddlernutrition/foods-and-drinks/picky-eaters.html Picky eaters and what to do <input type="checkbox"/> Benioff Children's Hospitals: https://www.ucsfbenioffchildrens.org/education/picky-eaters Parents' guide to picky eaters <p>Book for picky eating <i>Food Chaining</i> by Fraker and Fishbein</p>
Sleep Issues	<p>Sleep Hygiene</p> <ul style="list-style-type: none"> <input type="checkbox"/> Sleep Foundation: https://www.sleepfoundation.org/children-and-sleep/sleep-strategies-kids <input type="checkbox"/> Healthy Children: https://www.healthychildren.org/English/healthy-living/sleep/Pages/Sleep-and-Mental-Health.aspx <p>Encopresis</p> <ul style="list-style-type: none"> <input type="checkbox"/> YouTube: https://www.youtube.com/watch?v=SgBj7Mc_4sc <input type="checkbox"/> Stanford Children's: https://www.stanfordchildrens.org/en/topic/default?id=encopresis-90-P01992 <p>Enuresis</p> <ul style="list-style-type: none"> <input type="checkbox"/> YouTube: https://www.youtube.com/watch?v=EtF3cwheZSc https://www.youtube.com/watch?v=S-hGcEjpcJ8 <input type="checkbox"/> Family Doctor: https://familydoctor.org/enuresis-bed-wetting/ <p>Information about Melatonin</p> <ul style="list-style-type: none"> <input type="checkbox"/> Healthy Children: https://www.healthychildren.org/english/healthy-living/sleep/pages/melatonin-and-childrens-sleep.aspx <input type="checkbox"/> Children's Hospital: https://answers.childrenshospital.org/melatonin-for-children/ <p>Obstructive Sleep Apnea</p> <ul style="list-style-type: none"> <input type="checkbox"/> Kids Health: https://kidshealth.org/en/parents/apnea.html

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Information on Special Olympics Offerings

- ☐ **Young Athletes:** <https://www.specialolympics.org/our-work/inclusive-health/young-athletes> Special Olympics Young Athletes is an early childhood play program for children with and without intellectual disabilities , ages 2 to 7 years old. Young Athletes introduces basic sport skills, like running, kicking and throwing. Young Athletes offers families, teachers, caregivers and people from the community the chance to share the joy of sports with all children
- ☐ **Healthy Athletes:** <https://www.specialolympics.org/our-work/inclusive-health/healthy-athletes> Free health screenings and education to Special Olympics athletes in a welcoming, fun environment
- ☐ **Unified Champion Schools:** <https://www.specialolympics.org/our-work/unified-champion-schools> The Special Olympics Unified Champion Schools program is aimed at promoting social inclusion through intentionally planned and implemented activities affecting systems-wide change. With sports as the foundation, the three-component model offers a unique combination of effective activities that equip young people with tools and training to create sports, classroom and school climates of acceptance. These are school climates where students with disabilities feel welcome and are routinely included in, and feel a part of, all activities, opportunities and functions.

For information on any of these programs contact your local Special Olympics Office:

<https://www.specialolympics.org/programs>