

New Autism Diagnosis Resource Sheet

Receiving this resource sheet means your child probably just received an autism diagnosis. We want you to know that your child is still the same child as they were before the diagnosis – all the things you love about them and the dreams you have are still there. Being autistic is part of what makes them who they are and may help explain why they do, feel or act in certain ways. You will continue to be instrumental in building a great life for your child. We hope this resource sheet provides direction and support for your family on your journey. This resource sheet reflects collaboration between autistic adults, parents of autistic children, healthcare providers, and school staff. You will see some national resources, but we have tried to focus on Kentucky specific information and highlight those developed with autistic adults.

Learn More About Autism

Learning about autism will help you appreciate why your child feels or acts in certain ways.

Autism is a neurodevelopmental disability reflecting differences in the brain. These include communication and social differences as well as intense and sometimes unusual interests and different movement needs. Every autistic person experiences autism differently. It is currently believed that autistic people account for about 2-3% of our population. Autism is not a disease, but a valid human way of thinking and being.

Resources

- **What is Autism**
- **About Autism**
- **Autism 101**
- **The Meaning of Self Advocacy**
- **Books About Autism**

Connect With Other Families

A great way to learn more about supporting your autistic child is from others with experience doing it. Connecting with families who have an autistic child provides sense of community, belonging and understanding. In person or online, you can create a place where you can discuss similar needs, help each other by sharing information and resources envision all the possibilities for your child. This support and friendship helps navigate your journey and is necessary for maintaining good health.

Resources

- **Start Here Guide**
- **Regional family support groups**
- **KY Special Parent Involvement Network**
- **Family to Family**
- **13 Necessary Next Steps for Parents**

Get to Know Autistic Self-Advocates

We believe autistic adults are experts in autism. Autistic adults can help you understand autism, give you suggestions for or ways to help your child, and/or be a mentor as your child grows up. Autistic mentors show your child that it is okay to be autistic and model autism advocacy and self-determination skills. You can connect online (chat rooms, social networks) or at local autism groups.

Resources

- **Autistic Self Advocacy Network**
- **Autistic Women and Nonbinary Network**
- **Kentuckiana Autistic Spectrum Alliance**
- **A Curriculum for Self-Advocates**

Establish School Plans

School is a main activity of childhood through adolescence. It is important to plan to get your child a good education whether your child is already in school or will be starting school soon. Social, communication, thinking and sensory differences can make having success in school challenging. If your child has difficulties at school, they have rights at school. At public schools, the Individuals with Disabilities Education Act says your child can be evaluated to identify their strengths and support needs to develop a plan that helps them learn the same things and in a classroom alongside other students who do not have autism. At private schools, Section 504 of the Rehab Act may require schools to provide supports a student needs to learn.

Resources

- **Kentucky Early Intervention System**
- **KDE Autism Guidance Document (June 2023)**
- **Kentucky State Funded Preschool**
- **KY-SPIN Publications- IEP & 504 Infographics**

Seek Desired Supports and Services

Together, you and your child will determine your goals and supports you want. Supports and services access the expertise of health practitioners to help your child live their best life, with a goal of helping them successfully participate in the things they want to do. You may want supports to help your child communicate, socialize or respond to sensory experiences differently. You may also want to get additional support with your child's adaptive/self-help skills. Services should not try to make them less autistic. Instead, quality services look at your child, their strengths, and what they need help with to reach the goals you both have identified. They should also help your child understand their autism, advocate for themselves, and learn new skills that work best for their learning styles.

Resources

- **Kentucky Early Intervention System**
 - **ECMH Contact List**
 - **Autism Affirming Support Descriptions**
- Specific supports and services like art, play, speech, occupational, physical therapy, or mental health supports are available across Kentucky. You can access these in your region by collaborating with your **primary care doctor** or a **case manager** through your child's insurance company.

Explore the Larger Disability Community

Just like the autistic specific community we discussed above, there are also broad disability communities. You and your child can meet others with disabilities and their families. You can engage with these communities to build awareness of disability challenges and share best ways to navigate systems of support. You can also advocate to make society a better place for disabled people to be seen as valued and contributing members with equal rights.

Resources

- **Disability Rights Network**
- **Disability Rights Timeline**
- **Disability Justice**
- **Principles of Disability Rights**
- **American Disabled for Attendant Programs Today (ADAPT)**
- **The Association for Persons with Severe Handicaps (TASH)**
- **New Disabled South**

Support Participation

There are common challenges families experience in their daily lives. These tips and toolkits can help support the needs of your autistic child to participate in activities of daily living.

Resources

- **Sleep and Autism**
- **Toileting**
- **Feeding difficulties**
- **Dental care**
- **Blood draw**
- **Safety**
- **Transition to Adulthood: A Health Care Guide for Youth and Families**

Additional Resources

Information is power. These toolkits and other resources for families to explore supplement other action areas of this resource sheet.

Resources

- **Kentucky Advisory Council on Autism**
- **Supported Decision Making**
- **Life Course Tools**
- **Family & Youth Employment Checklists**
- **Resources and Supports for Families (KATC)**
- **Kentucky Protection and Advocacy**

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