

AUTHORIZATION OF BIENNIAL REPORT: SEPTEMBER 30, 2025

The Kentucky Advisory Council on Autism (KYACA) and the Kentucky Office of Autism provide this report in accordance with the provisions of <u>KRS 194A.624</u> which requires a biennial report be submitted by the *Advisory Council on Autism Spectrum Disorder* to the Governor, Legislative Research Commission, and the Commonwealth Council on Developmental Disabilities. This report contains information from State Fiscal Year 2024-2025.

While the original legislation uses the term *autism spectrum disorder (ASD)*, the current Council has amended the title of the KYACA to be *Kentucky Advisory Council on Autism* as this reflects and honors autism through a more strength-based perspective and through the <u>social model of disability</u>. This report will often use the term autistic (<u>identity first language</u>) instead of individual with autism (person first language). <u>Research</u> supports that most autistic adults prefer identity first language over person-first language.

AUTISM THROUGH AUTISTIC PERSPECTIVE:

What is Autism?

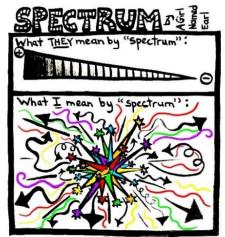
A neurodevelopmental disability characterized by social and communication differences and a need for sameness or repetition. These differences may be expressed in a variety of ways. For example, communication differences in autism include:

- Not speaking
- · Speaking only rarely or in specific situations
- Talking much less or much more than the average person
- Speaking more quietly or more loudly
- Speaking at a slower or faster pace
- Speaking with flat affect or in a singsong manner
- Speaking robotically or using "character" voices
- Whispering or speaking only about one or two topics

The same is true for social and sameness components of autism.



<u>Autism Infinity Sign: Symbol of Neurodiversity & Acceptance</u>



Exploding Perception

"Exploding perception" by Spectrum (A Girl Named Earl) illustrates the popular conception of a linear spectrum versus a model that depicts the many dimensions of neurodivergence.

AUTISM PREVALENCE:

In April 2025, the Centers for Disease Control and Prevention issued its <u>Autism and Developmental Disabilities</u> <u>Monitoring (ADDM) prevalence report</u>, which concluded that the prevalence of autism had risen to **1 in 31** births in the United States (3.23% of the population). It is important to note this study is for 8-year-old autistics who receive services. These prevalence numbers do not include those diagnosed later in life and under-represent the true number of autistic people in our country and in Kentucky.

OFFICE OF AUTISM

As a part of the Cabinet for Health and Family Services, the Office of Autism is housed within the Department for Behavioral Health, Developmental and Intellectual Disabilities (DBHDID). The office coordinates statewide efforts to enhance the quality of life and independence for autistics and provides support to their families and caregivers. The office is the center of a communication network sharing autism-related information among state agencies, and it provides administrative support to the advisory council to unify and promote initiatives aimed at improving Kentucky's system of care. In addition, the office works to increase the capacity of qualified providers of services through training opportunities in evidenced-based practices, and technical assistance to providers, professionals, and employers.



- Executive Director (1.0 FTE)
- DBHDID in CHFS
- · Staff to Council
 - a) Executive Committee
 - b) 3 subcommittees
 - 1. Early Childhood (0-5/8)
 - 2. School-Age (5-18/21)
 - 3. Adolescent & Adult (14 18/21+)
- Website <u>www.kyaca.org</u>
- Council Projects
- · Constituent calls & emails
- · Serve on state councils and workgroups
- <u>Biennial Report</u> to Governor from KYACA

Office of Autism Goals (Chart represents goals based on KRS 194A.624)	Completed Outcomes 7/2023 to 6/2025
Create a centralized location to coordinate statewide and regional efforts to enhance the quality of life and independence to individuals with autism (autistics) and to support their families and caregivers	 233 unduplicated new constituent concerns addressed 47 professional (not KYACA members) inquiries addressed 185 parent/family/self-advocate inquiries addressed 17 student inquiries addressed
Improve coordination of autism resources within the system of care supporting children and adults with autism; help make those resources available to families and self-advocates; and be the center of a communication network sharing autism-related information among state agencies	 13 presentations 29 committees 3 public events 14,162 website page views
Provide administrative support to the KYACA to unify and promote initiatives aimed at improving Kentucky's system of care	 Coordinated subcommittee meetings and projects Scheduled and prepared for quarterly meetings, including executive committee meetings Responded to inquiries by KYACA members and staff Coordinated strategic planning

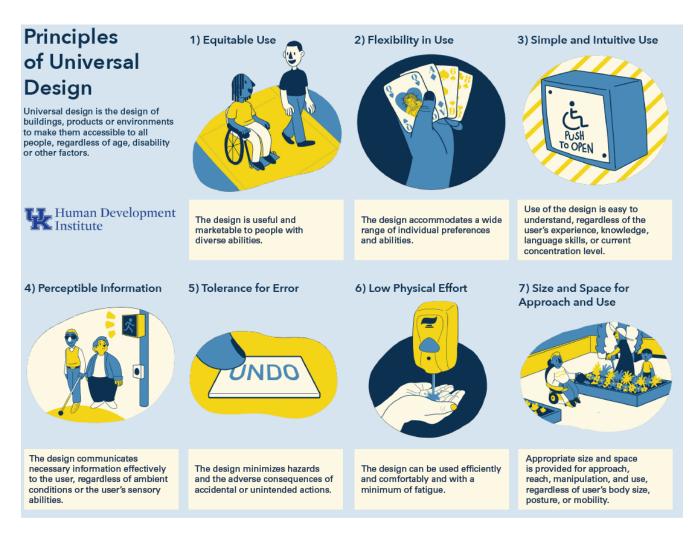
OFFICE OF AUTISM PROJECTS:

UNIVERSAL DESIGN INITIATIVE

With DBHDID commissioner support and as part of the 2024-2025 DBHDID strategic plan, the Office of Autism began this work by collaborating with UK Human Development Institute (HDI) to create virtual presentations from individuals with lived experience and/or disability professionals to introduce key common language and key concepts related to disability pride and universal design. All DBHDID central office staff were invited and encouraged by the commissioner to attend the one-hour virtual events:

All DBHDID staff virtual one-hour educational sessions:

- August 29, 2024 "Celebrating Disability Pride" (60 participants attended)
- October 14, 2024 "The Role of Identity in the Workplace" (67 participants attended)
- February 24, 2025 "Having Fun with Universal Design" (82 participants attended)
- June 30, 2025 "Creating Accessible Docs through UD" (64 participants attended)
- September 29, 2025 "Plain Language" (next event)



Informational slide about Universal Design from key partner University of Kentucky Human Development Institute.

The Office of Autism facilitated the creation of a Universal Design Team which began meeting monthly in March 2025. This team has nine members who consist of various staff that volunteered to serve across divisions in the department. The goals of this team are to create a positive disability culture, increase our department's understanding of universal design, and incorporate or embed universal design into DBHDID practices and policies.

Work Tasks

- Completing walk through of DBHDID physical space and identifying ways to improve space through universal design
 with partners from the University of Kentucky Human Development Institute (UK HDI), DBHDID leadership, and
 Cabinet for Health and Family Services leadership
- Improving building accessibility by cleaning out unnecessary furniture in the DBHDID 4th floor office spaces; identifying and requesting accessible bathrooms for all individuals; developing new office cubicle and other directional signage; and creating more functional space based on universal design
- Creating infrastructure for the team such as a shared drive for documents and resources
- Developing a list of disability terms to assist with educating DBHDID staff
- Collaborating with the DBHDID Trauma and Resilience and Racial Equity Teams

AUTISM IN THE COURTS (AITC)

In 2024, the Office of Autism assembled a team of justice-oriented autistics and qualified legal advisors to begin addressing the lack of the autistic community's understanding of the court system and the courts' lack of understanding autistics. This team decided to start with a series of video trainings. The first video is designed to support autistic people who may be new to interacting with the courts. The training discusses what to expect at the courthouse, the roles of court officers, how to behave in court, accommodations requests, and more. This video will be ready for release soon.

Meanwhile, AITC has created slides and a script for four brief videos designed for court officers. These explore autism basics, the brain-based reasons for unusual behaviors, the life experiences of autistic people, and best practices for communication. Once all trainings are recorded, the work group will continue to seek ways to support justice for autistics through work with Kentucky's legal systems.



Proposed Autism in the Courts logo by Erin Fitzgerald



Where do I sit?

- Choose a place to sit in the area behind "the bar."
- Remain seated until your case is called.
- You may get up to get a drink or use the restroom but come right back.
- If you need to talk to people sitting nearby, do this quietly.

Can I bring a service animal?

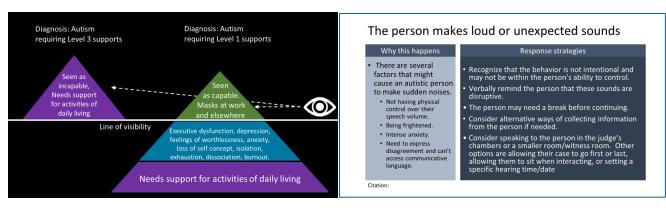
- •The Americans with Disabilities Act (ADA,1990) covers your right to bring a service animal to court.
- animal to court.
 •Courts are not required to allow emotional support animals, but many do allow them.

Service animal Dog or mini horse

- Specially trained to perform a specific task or tasks for one person.
 Under control at all times
- Protected by ADA



2 slides from Autism in the Courts for Autistic People explain courtroom norms and expectations.



2 slides from Autism in the Courts for Court Officers explain the reasons for some autistic differences.

KENTUCKY ADVISORY COUNCIL ON AUTISM (KYACA)

In November 2013, an initial executive order was signed by the Governor establishing the Kentucky Advisory Council on Autism (KYACA). A second executive order broadened membership of the committee, and a third broadened the role of the University of Kentucky and the University of Louisville. On April 1, 2016, the Governor signed Senate Bill 185 into law to create new sections of KRS Chapter 194A.623 and 194A.624 to create the Office of Autism and to establish the Advisory Council on Autism.

MISSION: The Advisory Council on Autism promotes collaborative efforts and advocates to improve systems of supports for autistics (individuals with autism).

VISION: Autistics (individuals with autism) of all ages are engaged in self-determined lives and valued citizens in the community.

The KYACA provides resources and supports across the lifespan in all the departments, offices and divisions identified as members of the council. Community members, including educational institutions, payers and employers, self-advocates, and additional state government agencies are key partners.

KYACA THREE LIFESPAN SUBCOMMITTEES

The subcommittees are comprised of a variety of state partners representing autistic self-advocates, families, university training programs, community mental health centers, state government programs, community agencies, and private practices. Subcommittee meetings are held quarterly and offer a forum for open discussion on autism topics, the opportunity to provide program specific updates, and working time towards strategic planning activities. The last strategic plan was completed in 2022 and has guided the work highlighted below.

Early Childhood Subcommittee (birth to age 5) works to identify strengths and challenges in ensuring Kentucky's system of care is moving toward system level coordination in the early screening, assessment, diagnosis, and intervention of autism in ages birth through age five.

Goal: Support families with children newly diagnosed with autism.

Strategic Plan Outcome: Developed a <u>resource sheet</u> for those with a family member newly diagnosed with autism. (See visual below).



New Autism Diagnosis Resource Sheet

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

About Autism

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

• Autism 101

• Books About Autism

• The Meaning of Self Advocacy

The Early Childhood Subcommittee is currently in the process of updating the resources in this tool as well as adding resources and language that is inclusive of all ages of autistics. Below is an example of language to autistics and their families that will be utilized in the updated resource sheet:

"This resource sheet was created to assist autistic people and their families, especially those who are new to the diagnosis. Autistic people think, communicate, and act in ways that differ from most people. Autism is not a disease, but one of many ways of being human. We have selected resources to help you build both a better understanding of autism

and a better world for all autistic people. This document 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."

School Age Subcommittee (ages 5-21) considers issues relevant to the lives of students and their families. Primarily, this subcommittee's work has focused on student bullying and suicide prevention efforts and recently developed a transition provision of high-quality services and programming to facilitate the best potential outcomes for autistics.

Goal: Support autistic youth transitioning from high school and providing prevention resources.

Strategic Plan Outcome: Developed a <u>Transition Resource Sheet for Students with Disabilities</u> targeted at students beginning transition in high school. The purpose of this transition resource sheet is to "support youth and families to make informed decisions about transition services for students with disabilities. This <u>transition resource sheet</u> is to be shared with youth prior to and during 504/IEP meetings (ages 13/14 to 18/21)." A user may find "an accessible version by navigating to <u>tinyurl.com/KYTPRS</u>."

Adolescent & Adult Subcommittee (18/21+) worked on three primary areas below:

- Restraint and Seclusion workgroup has been working to learn as much as possible about the use of restraint and seclusion in facilities housing adults and adolescents across the state. The group has developed surveys and will analyze the results of these before developing suggestions based on best practice standards.
- **Document Review workgroup** seeks to ensure that the KYACA's commitment to centering autistic voices and using non-pathologizing language is upheld in all our work. The workgroup created a <u>list of terms related to disability</u> in order to standardize the language used within the council.
- Autism Informed Employers workgroup assisted Innovative Supports for Autistic Workers (ISAW) in implementing an online learning course for employers. <u>Autism Informed Employers ISAW</u> (More information on page 8).

The Adolescent & Adult Subcommittee met quarterly and had presentations and discussions on topics such as Hart Supported Living Services, accessory dwelling units and their potential for housing autistics near family members, and a report on suicide and autistic youth. Most recently, discussions have focused on new and upcoming challenges communities may face due to changing federal laws and budget reductions.

Future Project Adolescent & Adult Subcommittee - KYACA Suicide Prevention Resource

KYACA's Adult/Adolescent subcommittee's work group on suicide prevention has made excellent progress on a toolkit addressing the needs of autistic youth and adults who are depressed or suicidal. While some excellent resources exist to address the problem of suicide in youth, these tend to be framed in ways that support neurotypical people while failing to account for some of the unique concerns around autism and suicide. For example, some of the signs that might indicate suicidality in a typical youth (avoiding people) can be standard behavior for an autistic counterpart, while signs specific to autism (such as abandoning a special interest suddenly) are not mentioned. This resource is an ambitious attempt to fill this important information gap to benefit self-advocates, families, and professionals.

The workgroup led by autistic representatives is developing an extensive toolkit which will be presented as a standalone website. The resource includes information on the 988 Suicide and Crisis Lifeline, including details that will help autistic callers decide if this is the right resource for them. Alternative hotlines are also referenced for their attention to privacy and confidentiality concerns. Many other state and national resources are represented, including self-advocacy groups and clinics specializing in neurodiversity affirming care. Other resources include highlights from Lisa Morgan's extensive work on autism and suicide. Lisa Morgan is a national expert in autistic suicide prevention and crisis supports and is an autistic adult with lived experience in this field. There are tools for evaluating suicidality and for developing a list of

reasons to live. When complete, the site will also feature written and video testimonials from autistic self-advocates and professionals. The workgroup estimates that the site will be live before the end of the calendar year.

KYACA MEMBERSHIP (KRS 194A.624)

KYACA invites individuals who are not members to serve on one or more of the three subcommittees listed earlier in this report (early childhood, school age, and adolescent and adult) and attend all public meetings either in person or via video conferencing. Self-advocates, parents, providers, and other interested members of the public are invited to participate in the subcommittees, which meet at least quarterly.

KYACA has sought to be inclusive of self-advocates and has broadened the council's collective understanding of autism to include perspectives beyond the medical model, including the <u>social model</u> and educational model. The council's understanding has grown through increased engagement with individuals with lived experience, both parents of autistics and autistics themselves. KYACA is always working to better understand and serve the autistic community, ensuring meetings are more accessible through resources like <u>ISAW Meeting Accessibility tools</u>, and expanding the representation on the council to include more autistic self-advocates. Finally, KYACA is working toward greater inclusivity by honoring the self-advocate's motto "nothing about us, without us." This ongoing growth is reflected in the addition of the word autistics in the mission and vision.



Member Agencies & Organizations

























- Department for Community Based Services
- Department of Public Health
- Department for Medicaid
- Department for Behavioral Health Developmental and Intellectual Disabilities
- Kentucky Early Intervention Services
- Office for Children with Special Health Care Needs



KYACA & OFFICE OF AUTISM PROJECT - INNOVATIVE SUPPORTS FOR AUTISTIC WORKERS

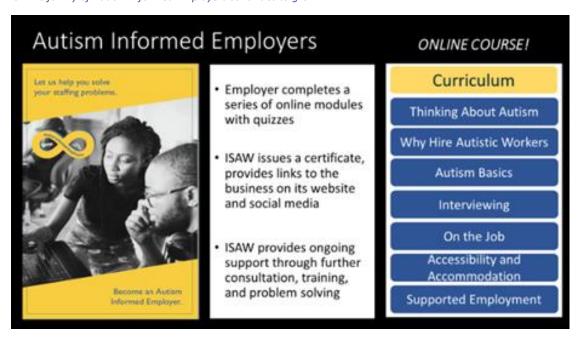
Innovative Supports for Autistic Workers (ISAW) Project of the University of Kentucky's Human Development Institute (HDI) is a training and consultation project funded by the Kentucky Office of Vocational Rehabilitation (OVR) and Kentucky Office of Autism to support businesses and increase the employment of autistic workers. Created in 2016 with a mission to provide training to Business Service Teams in the Kentucky Career Center, the project has expanded its scope and now offers its services at no charge to interested employers in the state.

Autism Informed Employers

In 2023, ISAW launched <u>Autism Informed Employers (AIE)</u>, an online training course for employers, employment specialists, and others engaged in the work of supporting autistics to gain and maintain employment. The course continues to attract new employers and businesses joining the AIE collective represented below:



ISAW's family of Autism Informed Employers continues to grow



Designed for employers and available to all free of cost, the AIE course can be found at HDI Learning.