



Biennial Report of the Kentucky Advisory Council on Autism

September 30, 2023

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INTRODUCTION

The Kentucky Advisory Council on Autism (KYACA) and the Kentucky Office of Autism provide this report in accordance with the provisions of [KRS 194A.624](#) 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 2022-2023. 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 [social model of disability](#). Through the report, you will see the use of both *ASD and autism* as our systems still often use *ASD*.

AUTISM PREVALENCE

In March 2023, the Centers for Disease Control and Prevention issued its [Autism and Developmental Disabilities Monitoring \(ADDM\) prevalence report](#), which concluded that the prevalence of autism had risen to **1 in 36** births in the United States (2.78% 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.

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. The office coordinates statewide efforts to enhance the quality of life and independence for individuals with autism 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. Table 1 presents KRS-defined goals for the Office of Autism.

Table 1 - Office of Autism Completed Outcomes

Office of Autism Goals (Chart represents goals from KRS 194A.623)	Completed Outcomes 7/2021 to 6/2023
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	<ul style="list-style-type: none">• 223 unduplicated new constituent concerns addressed• 52 professional (not KYACA members) inquiries addressed• 181 parent/family/self-advocate inquiries addressed• 21 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	<ul style="list-style-type: none">• 9 presentations• 22 committees• 3 public events• 2 visits to diagnostic or medical clinics• 15,876 website page views
Provide administrative support to the KYACA to unify and promote initiatives aimed at improving Kentucky's system of care	<ul style="list-style-type: none">• Coordinate 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

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 system of supports for autistics (individuals with autism).

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

The KYACA provides resources, services, 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 Membership

The co-chairs of KYACA are Governor-appointed and represent the University of Kentucky, Bev Harp, and the University of Louisville, Dr. Gregory Barnes. (See link for [KRS 194A.624](#) for more information).

KYACA invites individuals who are not members to serve on one or more of the three subcommittees and attend all public meetings either in person or via video conferencing. KYACA has three subcommittees based on developmental stages: early childhood, school age, and adolescent and adult. Self-advocates, parents, providers and other interested members of the public are invited to participate on the subcommittees, which meet at least quarterly and provide recommendations and strategies toward the tangible efforts of the KYACA.

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 [social model](#) and educational model. The Council's understanding has grown through increased engagement with individuals with lived experience, both parents of individuals with autism and autistics themselves. KYACA has begun the process to educate itself on understanding of autism, ensuring meetings are more accessible through resources like [ISAW Meeting Accessibility tools](#), and expanding the representation on the Council to include more autistic self-advocates. Finally, KYACA is working toward greater inclusivity by honoring self-advocates motto "[nothing about us, without us](#)." This ongoing growth is reflected in the addition of "autistics" in the mission and vision below.

KYACA Racial Equity Plan

Based on national autism research, there are significant racial inequities that exist in diagnosis and supports to autistics. For example, Hispanic children are 65 percent less likely and black children are 19 percent less likely than white children to be diagnosed with autism ([Aylward et al., 2021](#)). As a response to racial inequities, in August 2020, the KYACA began a process to integrate racial equity into all aspects of the Council and Subcommittees work by adopting Racial Equity Commitments and creating a Racial Equity Plan.

Equity outcomes:

- Adding Racial Equity Update and Discussion as a regular agenda item of Council and Subcommittees.
- Encouraging people of color to apply as citizens at large or self-advocates representatives to KYACA.
- Encouraging people of color to engage with KYACA and its subcommittees as volunteers and advocates.
- Increasing diversity representation on Council & subcommittees and to provide a diverse perspective.
- Created a Racial Equity Workgroup to drive change within the Council and Subcommittees.

KYACA Strategic Plan

In Spring of 2022, KYACA completed a Strategic Plan that created the Elevator Speech and integrated racial equity into the goals and objectives under each of the three subcommittees.

ELEVATOR SPEECH: The KYACA is a collaborative of autistics and allies who work to increase respect, understanding, and autonomy for all autistic Kentuckians, especially black, indigenous, people of color (BIPOC), through advocacy, education and growing circles of support.

KYACA SUBCOMMITTEES & STRATEGIC PLAN PROGRESS

Early Childhood Subcommittee 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. The subcommittee is comprised of a variety of stakeholders 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 provide stakeholders with the Office of Autism and other subcommittee updates, a forum for open discussion on autism topics, the opportunity to provide program specific updates and working time towards strategic planning activities.

Goal: Support families with children newly diagnosed with autism

Strategic Plan Outcome: Developed a [resource sheet](#) for those with a family member newly diagnosed with autism. (See visual below)



New Autism Diagnosis Resource Sheet

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

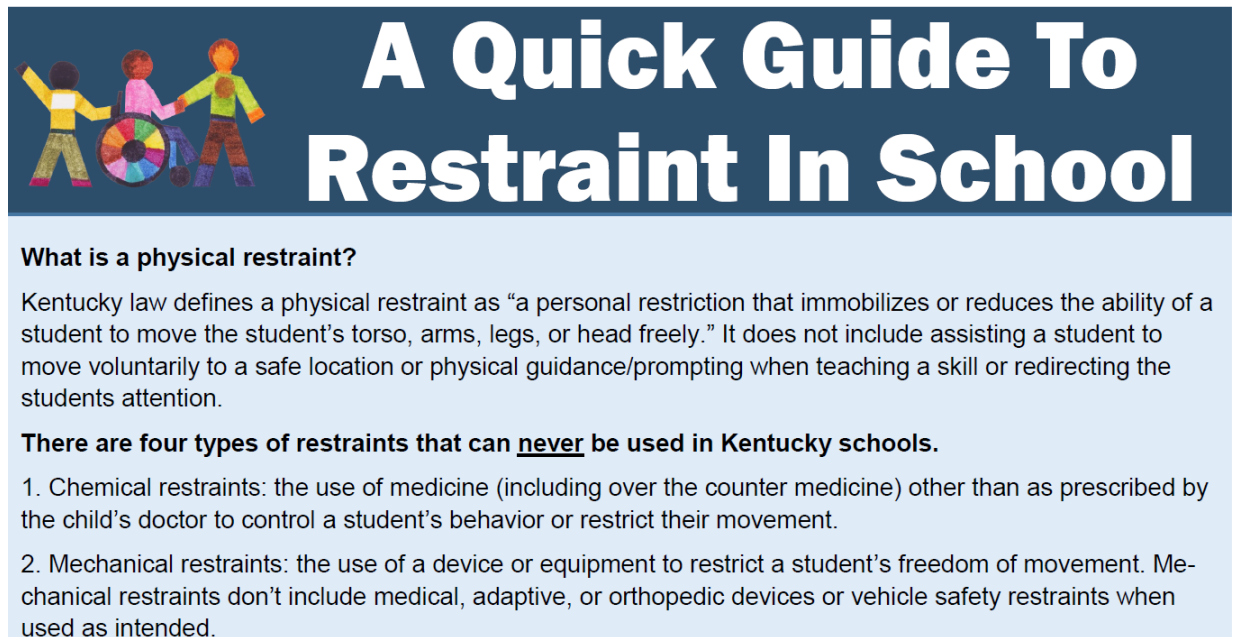
The resource sheet reflects collaboration between autistic adults, parents of autistic children, health care providers and school staff. As a result and unlike other available guidance documents, this resource sheet includes some national resources, but the committee focused on Kentucky-specific information and highlight those developed with autistic adults. The final draft includes key actions for users (i.e., learn more about autism, connect with other family members, get to know autistic self-advocates, establish school plans, seek desired supports and services, explore the larger disability community, support participation, additional resources), why these actions are important and links to specific resources. The committee also developed a survey to gather information on how the resource sheet was disseminated and used.

School Age Subcommittee considers issues relevant to the lives of children and young adults ages five through 21, and their families. Primarily, this subcommittee's work has focused on the provision of high-quality services and programming to facilitate the best potential outcomes for autistics.

Goal: Address restraint and seclusion in schools

Strategic Plan Outcomes:

1. Increase the number of subcommittee members participating by a minimum of two people for each area including autistics and persons of color, at the subcommittee meetings. This goal has been met.
2. Gather and review data regarding the use of restraint and seclusion in schools and make recommendations and a plan of action to address this issue. The subcommittee worked with Kentucky Department of Education staff to review data which lead to the revision of a [Kentucky Department of Protection and Advocacy Restraint Guidance Document](#). This document has been shared with families and family organizations throughout the state. (See visual below)



Adolescent & Adult Subcommittee has focused on improving services across the life span for autistics and understanding needs as they relate to transition from school into adult life and the opportunities and barriers in Kentucky to community integration as an adult. The Subcommittee encourages self-advocate and family participation. This subcommittee, above all others, has led in the growth of understanding autism through the perspective of autistics. The Adolescent and Adult subcommittee has focused on employment issues and inclusion of self-advocates over the past two years. Meeting topics have included issues with waivers, housing regulations, restraint and seclusion and Hart Supported Living. Subcommittee meetings have also featured presentations on employment data, autism and gender, and autistic identity and culture. The subcommittee established four workgroups with two workgroups under each goal below.

Goal 1: Address violence and abuse toward autistics.

Strategic Plan Outcomes:

1. Will conduct a study of restraint and seclusion practices in long-term facilities across the state and recommend policy change. (Restraint and Seclusion workgroup)
 - a. Reviewed policy relevant to restraint and seclusion at the Kentucky Department of Juvenile Justice and offered suggested guidance on regulation updates for individual advocates.
 - b. Will continue to look at other policies and practices in facilities.
2. Will review current council projects and official documents to identify potential ways these might unintentionally contribute to the climate in which violence against autistic people lives. (Document Review workgroup)

- a. Developed a rubric for assessing documents used on the Council’s website as well as any new documents created. Rubric has been utilized.
- b. Will continue to review website and document with this rubric and using racial equity tools.

Goal 2: Increase employment opportunities for autistic workers and jobseekers in Kentucky.

Strategic Plan Outcomes:

1. Will develop an inventory of potential employers and ensure that they receive the training and support they need to hire and retain autistic workers (Autism-Informed Employers workgroup.)
 - a. Assisted ISAW in the development and completion of a series of [online training modules](#).
2. Will work with the Employment First Council to develop a guide to employment resources for autistic jobseekers (Employment Handbook workgroup.)
 - a. Work was put on hold due to workgroup leadership change and new appointed members of the Employment First Council. Plan to begin work Fall 2023 to coordinate with a workgroup of the Employment First Council on the creation of a guidebook for jobseekers.

KYACA PROJECT – INNOVATIVE SUPPORTS FOR AUTISTIC WORKERS

[Innovative Supports for Autistic Workers \(ISAW\) Project](#) of the University of Kentucky’s Human Development Institute and is funded by Kentucky’s Office of Vocational Rehabilitation (OVR) and the Kentucky Office of Autism. Established in 2016 to support business service teams in the Kentucky Career Centers, ISAW has expanded to include training opportunities for all employers and employment support professionals.

Autism Informed Employers Initiative

For much of 2022 and early 2023, ISAW has focused efforts on creating a new online training course. The Autism Informed Employers (AIE) initiative has been designed to allow employers to access ISAW training easily at their own convenience. Seventeen modules in seven different categories have been created and are soon to be available on HDI Learning. The curriculum includes basic and advanced information about autism; accessibility and accommodations; and many examples of potential workplace scenarios. Upon completing the series, an employer or employment specialist will have gained confidence in their abilities to hire, supervise and retain autistic workers. A module on working with supported employees is included as well as information about co-occurring conditions.

Trainings and Presentations

ISAW offers training to employers throughout the state. ISAW provided training to 10 supervisors throughout UK’s Chandler Medical Center and two more to departments within the University of Kentucky. Supervisors at Northern Kentucky University also received ISAW training, as did their project SEARCH team. ISAW trained at least 10 businesses across the state including Ortho Cincy and Norton Healthcare as well as several smaller businesses, bookstores, salons and coffee shops in Lexington and Louisville. ISAW training was also conducted for two provider agencies. In addition to the core trainings offered to employers, ISAW delivered presentations to at least 12 groups throughout the state, including information on autism and the social model of disability for supervisors in the Kentucky Community and Technical College system and tips for supporting youth who are preparing to enter the workforce for counselors at Georgetown Counseling Center. ISAW presented at three state conferences for the Association of People Supporting Employment First (APSE), the Kentucky Exceptional Children’s Conference and the Kentucky Library Association’s annual conference. Project staff participated in CCDD’s Partners in Policymaking for 2022 and UK’s Summer Leadership Experience Camp. Additionally, the project presented information and updates on ISAW to the state’s HB144 committee, HDI’s Consumer Advisory Council, and the Kentucky Advisory Council on Autism. Panel presentations including

ISAW staff were hosted by Agnes Scott College (Georgia), Campbell County Library and UK's Human Development Institute. ISAW also discussed employment for autistic people on the Southeast ADA Center's podcast. ISAW is currently working with several autistic self-advocates on a virtual workshop for jobseekers to be held late this summer. A second workshop for employers and employment professionals will be presented in the fall.

Consultations

ISAW offers no-cost consultations to all employers in Kentucky. In 2022-23, 11 businesses consulted with ISAW on hiring or retaining autistic employees. ISAW also serves Kentucky Community Rehabilitation Partners (CRPs), OVR staff and other professionals who work with jobseekers. Employment Specialists from five agencies received support from ISAW in 2022-23; The project also provided consultation for mental health providers, parents and other community members.

Direct supports to employed autistic workers and jobseekers

One of ISAW's goals is to support the workplace skills of employed autistic individuals to help them remain on the job. Short-term supports, including resume review, interview practice and counseling on topics such as disclosure and accommodations were provided to six jobseekers and three current employees. Two employed autistic workers and one jobseeker are currently receiving long-term supports.

ISAW Consultants

By providing information derived from lived experiences, as well as the most current peer-reviewed literature, the project strives to increase understanding of both the assets and support needs of autistic workers. The involvement of autistic staff and consultants are crucial to the work ISAW does. Consulting with ISAW allows workers with limited experience to develop new skills as they create written or video reports. For 2022, ISAW interviewed 10 consultants about their experiences with seeking accommodations. The resulting reports are being used in the development of new presentations and training modules. In 2023, six consultants participated in ISAW's Autistic Worker Appreciation campaign during April; one consultant is currently interning with the project.

Products

ISAW produces newsletters, infographics, and fact sheets for employers and employment support professionals. Most recently, infographics have featured service animals and more general information on understanding and providing accommodations. Newsletters were emailed to approximately 200 community partners in the summer and winter of each year.

In addition to the Autism Informed Employers initiative, ISAW created a new core training presentation featuring information about co-occurring conditions and how these can create different experiences and different support needs for autistic workers. A new series of handbooks for jobseekers who need support with reading is in development, with one handbook completed and a second being edited. The first handbook contains information about OVR services and supported employment as well as cover letter templates and tips for interviewing. Other products included a new promotional flyer for social media as well as Autism Appreciation month posters featuring 10 autistic workers at the University of Kentucky.

KYACA PARTNERSHIP HIGHLIGHTS

University of Louisville (See APPENDIX for narrative)

University of Louisville

FY 22-23 Data at a Glance

Norton Children's Developmental Center



2,661

Diagnostic service encounters



859

Unique patients

Kentucky's Early Intervention System (KEIS)



247

Early identification evaluations

Office for Children with Special Health Care Needs

Kentucky Autism Initiative in Treatment, Training, and Research (KAITTR)

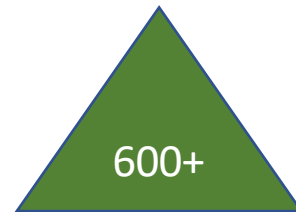


5

Clinics

1,300 +

Service encounters



600+

Follow up consultations

Systematic Treatment in Autism and Related Disorders (STAR) Program



7,716

Service encounters



2,868

Unique patients

KY LEND Program

The Kentucky Leadership Education in Neurodevelopmental and Other Related Disabilities ([KY LEND Program](#)) is part of a national network of 60 LEND programs. LEND programs share the overall mission of improving the health of infants, children and adolescents with neurodevelopmental and related disabilities. The first goal of the KY LEND is to implement and evaluate an interdisciplinary training program as a consortium among the University of Kentucky, the University of Louisville, and Eastern Kentucky University. Faculty from each university share information and resources with the trainees and each other, resulting in greater collaboration than was possible before the KY LEND. The second goal is to apply lessons learned from the KY

LEND to improve services and outcomes for people with neurodevelopmental disabilities and their families. The faculty and students of the KY LEND are carrying the message of interdisciplinary, evidence-based approaches in each of their careers and lives. Placement opportunities are located at 46 different sites, including eight clinical settings, schools across Kentucky, including the School for the Blind, and diverse online opportunities including webinars, courses, and training programs in a variety of disciplines, (e.g., speech and language therapy, physical therapy, early childhood and special education and adaptive dance.)

The KY LEND has been operating since July 2021. It served nine LEND trainees in 2021-2022 (Year 1), and nine trainees in 2022-2023 (Year 2). From among a highly competitive group of applicants, 10 trainees were selected to begin in August 2023. The KY LEND faculty and leadership team include 16 professionals from the fields of neurology, developmental behavioral pediatrics, rehabilitation science, special education, early childhood education, clinical psychology, educational psychology; occupational, physical, and speech and language therapies; public health, family and self-advocacy. The KY LEND also includes a self-advocacy and family rotation for all trainees.

CONCLUSION

This report represents a summary of the work of the Kentucky Advisory Council on Autism including the dedicated work of three lifespan subcommittees, Innovative Supports for Autistic Workers Project and Partnership Highlights. As the KYACA promotes collaborative efforts and advocates to improve system of supports for autistics, it has been paramount that the voice of autistics leads the way toward meaningful change. The Council moved forward with recommending five self-advocates be appointed to the Council to enrich and ground the Council's work in an autistic perspective. A special thanks to Governor Beshear for making these appointments. Establishing and maintaining collaborative relationships with Council agencies has proven productive in moving the KYACA toward the vision that autistics of all ages are engaged in self-determined lives and valued citizens in the community. Please see the APPENDIX section for additional information and data from KYACA Council Partnerships.

APPENDIX - KYACA PARTNERSHIPS

The following describes KYACA partner agencies' collaborative efforts to support autistic people/individuals with autism, their families, and the community-at-large.

University of Kentucky Human Development Institute

Brief Overview: The Human Development Institute (HDI) is Kentucky's University Center on Disability. HDI includes the University Center for Excellence in Developmental Disabilities Education, Research and Service (UCEDD) and Kentucky's Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND). HDI's mission, informed by the lived experience of people with disabilities, is to advance efforts that build inclusive communities; address inequities, and improve the lives of all people who experience disability across the lifespan. With over 70 projects and nearly 350 interdisciplinary full and part-time staff, HDI is a major unit administered through the University's Office of the Vice President for Research. Priority areas at HDI are: Early Childhood and Education, Leadership and Self Advocacy, Employment, Health, Universal Design and Assistive Technology and Research and Evaluation.

While many, if not all projects reach families and individuals with autism, the following projects are key collaborators with the Office of Autism and Council partners:

- **Community Work Transition Program** - The Community Work Transition Program (CWTP) helps students with disabilities gain skills and obtain resources to be career ready through services provided by an Employment Specialist. The CWTP is designed to provide students with a variety of opportunities and experiences in preparation for competitive integrated employment. The program includes both Pre-Employment Transition Services (Pre-ETS) and Individualized Transition Services (ITS), with a primary focus on ITS. It is a cooperative effort between participating local education agencies, the Kentucky Department of Education, Office of Vocational Rehabilitation and the Human Development Institute at the University of Kentucky.
- **Kentucky Supported Higher Education Partnership** – In Kentucky, only 18% of students with disabilities were enrolled at a college or university in the year following their exit from high school. The Kentucky Supported Higher Education Partnership (KSHEP) is a network of Institutions of Higher Education across the state offering inclusive higher education programs for students with intellectual and developmental disabilities, such as Comprehensive Transition and Postsecondary (CTP) programs.
- **Innovative Supports for Autistic Workers (ISAW)** - As a project of the KYACA, see p. 7 of this report for detail of ISAW.
- **Kentucky Peer Support Network Project** - The Kentucky Peer Support Network Project created to support development of Peer Support Networks in schools around Kentucky.
- **Kentucky Supported Employment Training Project** - Kentucky's Supported Employment Training Project provides support for professionals who in turn support people with disabilities with finding good jobs. This work is sponsored by the Kentucky Office of Vocational Rehabilitation and the Kentucky Division of Developmental and Intellectual Disabilities.
- **IPS Supported Employment Project** - The purpose of the IPS Supported Employment Project is to implement evidence-based Supported Employment for people with serious mental illness. The goal is to develop high-fidelity supported employment services and to increase access to these services for adults with serious mental illness throughout the commonwealth, and to improve the overall employment rate for individuals who want to work.

- **HDI Evaluation Unit** - The HDI Evaluation Unit's mission is to provide high quality and high utility evaluation services to diverse stakeholder groups and to do so in culturally responsive ways. The Evaluation Unit is committed to collaborating with stakeholders to explore the most efficacious ways in which evaluation results can be used to improve program effectiveness. An additional role of the HDI Evaluation Unit is to make meaningful contributions to evaluation theory, methodology and practice.
- **HDI Center for Assistive Technology Services (CATS)** is the regional Assistive Technology Regional Center (ATRC) serving Lexington and the surrounding region. The objective of HDI CATS is to provide statewide comprehensive assistive technology (AT) activities in accordance with the federal Assistive Technologies Act of 1998, as amended. AT is any item or piece of equipment (both low-tech and high-tech) used to improve and/or maintain independence in the home, at work, school or play.
- **Kentucky Learn the Signs. Act Early Ambassador** – HDI hosts Kentucky's Act Early Ambassador program and serves as liaison to support the work of Act Early State Teams and national initiatives to improve early identification of developmental delay and disability, and promote the adoption and integration of “Learn the Signs. Act Early” resources into systems that serve young children and their families.
- **Kentucky Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND)** - The KY LEND Program is part of a national network of LEND programs. LEND programs share the same overall mission of improving the health of infants, children, and adolescents with, or at risk for, neurodevelopmental and related disabilities. A major focus of LEND is to increase the number of professionals with the knowledge and skills to provide evidence-based screening, diagnosis, and treatment of neurodevelopmental disabilities, including autism.
- **Child Care Aware of Kentucky** – HDI administers Child Care Aware of Kentucky, committed to ensuring families have access to safe, affordable, quality care. The goal is to improve childcare quality through training and technical assistance to childcare providers and connecting the community to resources that support quality childcare.
- **University Center for Excellence in Developmental Disabilities Education, Research and Service** – As Kentucky's UCEDD, HDI's core functions are to provide preservice preparation, services (including technical assistance, community education, and direct services), research and information dissemination. and its sister agencies, the Commonwealth Council on Developmental Disabilities and the Kentucky Division of Protection and Advocacy form the state's Developmental Disability Network. This network is funded through the Developmental Disabilities Assistance and Bill of Rights Act of 2000 and is administered through the U.S. Office of Intellectual and Developmental Disability, within the Administration on Disabilities at the Administration on Community Living, U.S. Department of Health and Human Services.

University of Louisville

The Norton Children's Autism Center (NCAC)

The Norton Children's Autism Center (NCAC) is the clinical program of the University of Louisville Autism Center (ULAC) but still remains a collaborative partnership between the College of Education and Human Development's Kentucky Autism Training Center (KATC) and School of Medicine *Systematic Treatment of Autism and Related Disorders Program (STAR Program)*, *Norton Children's Developmental Center (former Weisskopf Center)* and *Norton Children's Division of Pediatric Behavioral and Mental Health (former Bingham Clinic)*. As the reported incidence of autism continues to increase, the NCAC has responded to meet the ever-growing need for evaluation, diagnosis and treatment. The NCAC's ongoing mission is to provide

comprehensive services by developing partnerships of leading experts to create effective interventions and advance research and training, targeting each child's specific needs while fostering group thinking and strategies among practitioners. This approach allows parallel treatments to occur and makes the best use of the time available.

Norton Children's Developmental Center (former Weisskopf Center)

At the [Norton Children's Development Center](#) (NCDC), the diagnosis of ASD is made through an integrated approach utilizing the expertise of an interdisciplinary team of professionals that combines information provided by family members regarding the child's developmental history in combination with behavior observation and formal evaluation. Specific practice parameters for the diagnostic assessment of ASD have been published by the American Academy of Neurology (AAN), the American Academy of Child and Adolescent Psychiatry (AACAP), the American Academy of Pediatrics (AAP) and the American Occupational Therapy Association. Consistent with these parameters, integrated evaluations provided at both centers routinely are provided by a child psychologist, and addition of a developmental/behavioral pediatrician and speech and language pathologist where appropriate. Other disciplines, such as occupational therapy, social services and clinical genetics participate on an as needed basis. *The Centers have access to this full array of services and clinical expertise centrally located to comply with the best practice guidelines from AAN, AACAP and AAP.* In fiscal years 2022-2023, there were 2,661 diagnostic service encounters at the NCDC Louisville location in support of 859 unique patients.

Systematic Treatment in Autism and Related Disorders (STAR) Program

Intervention services are offered through the Systematic Treatment in Autism and Related Disorders (STAR) Program at the [Norton Children's Autism Center](#) (NCAC). This intervention program is designed specifically for children with ASD with an emphasis on coaching families, client engagement, and learning that can be carried over to home, community and educational settings. Family-centered and individualized *STAR Program* evidence-based services include competency development, assessment, and outcomes and long-term support and follow-up. In FY 2022-2023, there were 7,716 service encounters in the support of 2,868 unique patients. The medical consultation practice including pediatric neurology, pediatric psychiatry, and developmental behavioral pediatrics had 4,294+ service encounters, which supported 2,147+ individual patients and their families.

KEIS (formerly First Steps) Promoting Early Identification

The University of Louisville School of Medicine, Department of Pediatrics, Developmental and Behavioral Pediatrics division continues its key partnership with CHFS-DPH targeting early identification. Kentucky's Early Intervention System (KEIS) process improvement activities continue to streamline eligibility and evaluation procedures for children suspected of ASD. Through the Cabinet for Health and Family Services' Department for Public Health (CHFS-DPH) Record Review contract, the University of Louisville has provided statewide training and technical assistance to KEIS providers on use of and interpretation of key findings when using early screening and diagnostic measures. Record review approved intensive level diagnostic evaluations are performed at Norton Children's Development Center. This collaboration has led to early identification evaluations for ASD for 127 children under age three in FY22 and 122 children under age three in FY23.

Kentucky Autism Training Center (KATC)

Kentucky Autism Training Center (KATC) was established in 1996 by the Kentucky General Assembly to serve as a statewide resource for families and educators. KATC is a part of University of Louisville's College of Education and Human Development (CEHD) and is housed on the Kosair Charities campus. KATC is funded through a variety of sources and is overseen by the Kentucky Council on Post-Postsecondary Education. KATC's mission is to strengthen Kentucky's systems of support for autistics by bridging research to practice and by providing training and resources to families and professionals. KATC is committed to improving the quality of life for autistics in the Commonwealth.

To achieve this statewide mission, KATC collaborates with several KYACA partners such as the Kentucky Department of Education, University of Kentucky, Office of Vocational Rehabilitation, Department for Public Health, Office for Children with Special Health Care Needs, Office of Autism and many others. KATC supports individuals, families, educators, and service providers by providing training and via the development and/or sharing of resources. For more information, see [Annual Report](#)

Kentucky Department of Education (KDE)

The Kentucky Department of Education (KDE), Office of Special Education and Early Learning (OSEEL) continues to partner with the Kentucky Advisory Council on Autism (KYACA). Through this partnership and the United We Learn initiative, the KDE aims to create a more vibrant experience for every student, encourage innovation in schools, and create a bold new future for Kentucky's schools through collaboration with communities. Additionally, the OSEEL works to improve educational outcomes for exceptional and early learners through training and coaching, technical assistance and guidance resources for local districts, state schools and parents.

The KDE, Kentucky Autism Training Center (KATC), the Kentucky Special Education Regional Technical Assistance Centers (SERTACs) and school districts have been receiving training on how to educate students with Autism Spectrum Disorder (AUT). Some schools have become training/observation sites for other districts to send new and master teachers for learning opportunities. The SERTACs assisted districts with setting up these sites per the guidelines set by KATC. Additionally, the SERTACs support teachers as they implement Individual Education Programs (IEPs) for students with AUT.

In collaboration with the Early Childhood Regional Training Centers (RTCs), the KDE, KATC and KYACA have developed statewide training for preschool teachers, assistants and parents to further knowledge and understanding of autism to ensure students are successful within preschool environments. These groups have been working to identify strengths and challenges in Kentucky's system of care through the coordination of early screening, assessment, diagnosis, and intervention of AUT ages birth through age five.

The KDE, KATC, and the KYACA have also collaborated on Autism Guidance for Kentucky school districts. In November 2017, this guidance became available on the KDE website to assist school districts and parents through the process of acquiring evaluations, services, and modifications for their students with autism between the ages of three and 21 to enable them to be successful in their environments. In 2023, the KDE, KYACA and KATC collaborated to update and revise the guidance. The KDE website also houses resources related to autism and special education.

Department for Public Health (DPH)

The Kentucky Part C Coordinator is an appointed member of the KYACA, representing the Kentucky Early Intervention System (KEIS), and participates as a member of the early childhood subcommittee. Data on the number of toddlers identified with autism spectrum disorders and barriers to identification are provided to the KYACA. KEIS procedures are modified based on the information gained during council meetings. The KEIS continues to use specialized screening for possible autism spectrum disorder in toddlers. District Child Evaluation Specialists administer the Modified Checklist for Autism in Toddlers-Revised (MCHAT-R) with follow-up questions and the Screening Tool for Autism in Toddlers and Young Children (STAT).

Department for Medicaid Services

The Department for Medicaid Services (DMS) continues to provide behavioral health services authorized through the State Plan. Licensed Behavioral Analysts (LBA) and Licensed Assistant Behavior Analysts (LABA) continue to provide services as independently licensed practitioner and associates under supervision as well as offer services in Behavior Health Services Organizations and Behavior Health Multi-Specialty Group

provider type settings. Beginning January 1, 2019, the Department for Medicaid Services (DMS) added the billing codes specific for Applied Behavior Analysis on the Behavioral Health and Substance Use Disorder fee schedules. This will enable DMS to gather information on utilization of services provided by LBAs and LABAs.

In 2023 The Division of Community Alternatives underwent a reorganization, and the name was changed to The Division of Long-Term Services and Supports. Kentucky offered the first 1915(c) Home- and Community-Based Services (HCBS) waiver program for the elderly and individuals with disabilities in 1987. The DMS now offers six HCBS waiver programs to meet everyone's unique needs. DMS continues to focus on transforming 1915(c) HCBS waiver coverage and enhancing service quality throughout the Commonwealth.

1915(c) HCBS Rate Study

As part of Kentucky's enhanced FMAP spending plan, a new study of 1915(c) HCBS waiver rates is underway. The rate study aims to develop a sound payment and rate-setting methodology necessary to meet federal requirements and make updates to Kentucky's HCBS reimbursement rates. Review the [Rate Study Briefing](#) and the first [Enhanced Federal Funding for HCBS update](#) for detailed information about the rate study.

To assist with the rate study, [DMS formed a work group](#) of waiver providers, provider association representatives, state agency leaders, advocates and state legislators to provide input throughout the rate study. Recordings of work group meetings and meeting materials are available on-demand. Questions about the rate study can be [emailed to the DMS Rate Study Work Group](#).

Children's Waiver Feasibility Study

The Cabinet for Health and Family Services is [studying the need for and feasibility of creating an HCBS waiver for children](#). The study is focused on the possibility of serving children with severe emotional disturbance and children with intellectual disabilities or related conditions, including children with autism spectrum disorder. The study will also evaluate population data, provider ability to serve an added population, and the potential cost of an added waiver.

Department for Behavioral Health Developmental and Intellectual Disabilities (DBHDID)

Kentucky Department for Behavioral Health, Developmental and Intellectual Disabilities' mission is to promote health and well-being by facilitating recovery for people whose lives have been affected by mental illness and substance use, supporting people with intellectual or other developmental disabilities and building resilience for all. DBHDID's vision is for all Kentuckians to have access to quality services and supports to live full and healthy lives. Like pillars of strength, the DBHDID mission and vision are also supported by the values held by DBHDID, which can be found on its website: <https://dbhdid.ky.gov/kdbhdid/>

Additionally, DBHDID is responsible for the administration of state- and federally funded mental health and substance use prevention, treatment and recovery services throughout the Commonwealth. DBHDID seeks to empower each person to realize his or her place in the community as a citizen of the Commonwealth of Kentucky. To accomplish this mission, DBHDID partners with and supports persons with mental illness, substance use, and/or intellectual or developmental disabilities, families, advocates, stakeholders, and government agencies.

DBHDID Collaborations & Office of Autism

- The Office of Autism participates in bi-weekly DBHDID Executive Team Staff meetings hosted by Dr. Katherine Marks, DBHDID commissioner.
- The Office of Autism and DBHDID continue to work closely with the Department for Medicaid Services with the alignment of 1915(c) waivers and the design of available services and accessible delivery systems. Three of the existing waivers include individuals with autism and those with intellectual and/or other developmental disabilities. These waivers include the Home and Community

Based waiver, the Supports for Community Living Waiver and the Michelle P. Waiver. A new waiver designated for providing services for children is under current study.

- DBHDID continues to actively facilitate the 988 Planning Coalition and workgroups to transform the crisis continuum of care that started with the launch of 988 in July 2022. Kentucky's 988 crisis calls centers continues to build capacity to answer the increased volume of calls, chats, and texts to 988 from Kentuckians in crisis in SFY23.
- Kentucky's 988 crisis call centers, in collaboration with DBHDID, are working to ensure 988 contacts are connected to local resources such as services for mental health, substance use and intellectual or developmental disabilities.
- DBHDID assisted in the development of an additional Crisis Intervention Team (CIT) 2 training, which consists of 24 hours of total training. The CIT Advisory Boards surveyed the state regarding gaps in training topics and the response to the survey was a pilot of the CIT 2 Training in June 2021 in the Louisville area. This training now includes a block of training on Autism.
- DBHDID provides consultation to Kentucky Department of Education on guidance documents related to student, family and staff mental health and well-being as well as school practices and policies related to trauma, resilience, mental health, substance use, secondary trauma, etc. This consultation to KDE includes the intersection between trauma and equity, and the necessity of addressing equity as part of being trauma-informed and resilience-oriented. DBHDID provides consultation to and collaborations with other organizations on guidance documents related to student, family and staff mental health and well-being as well as practices and policies related to trauma, resilience, mental health, substance use, secondary trauma, etc. This work builds content knowledge and skills to address the intersection between trauma and equity and the necessity of addressing equity as part of being trauma-informed and resilience-oriented. Example collaborations include:
 - Kentucky Youth Health Network (a collaboration between the Department for Public Health and Kentucky Department of Education Whole School, Whole Community, Whole Child: Training sessions on Positive and Adverse Childhood Experiences.)
 - Kentucky Office of Autism: provided support through the DBHDID Trauma and Resilience Team – Tal Curry is an active member of the team.
 - Department of Public Health/ Office of Health Equity: Consultation and part of the planning team for a project to enhance school-based health equity; brought DPH and KDE together to partner on this.
 - Bounce Coalition: training and consultation to Bounce Trainers on integrating positive childhood experiences and HOPE Building Blocks into their work.
 - Collins Lane Elementary School/ Frankfort Kentucky: staff training on Trauma-Informed Discipline (including how to support neurodiverse youth in school settings)
 - System of Care Academy: Training session on integrating Positive Childhood Experiences into System of Care programs, services, approaches
- University of Kentucky Human Development Institute (UK HDI) and the Office of Autism have created a centralized [website](#) in Kentucky to coordinate resources, services and supports for self-advocates and families of persons on the autism spectrum. UK HDI maintains and continues the development of the website for the Advisory Council on Autism and the Office of Autism. This website coordinates state and national resources related to Autism. It also serves as a centralized location for self-advocates, parents, and professionals to find service information, meeting times and locations, and resources across disciplines and the lifespan of the service delivery system.
- The Office of Autism also collaborates with UK HDI to promote the development of services and supports to transition youth and adults on the autism spectrum, also referred to as Innovative Supports for Autistic Workers (ISAW) at the University of Kentucky Human Development Institute (UK HDI). Innovative Supports for Autistic Workers is a training and consultation project promoting increased hiring and retention of autistic employees. The project works with Kentucky's Office of Vocational Rehabilitation (OVR) and the Kentucky Office of Autism to support businesses, employment specialists,

and other interested parties in their understanding of the unique needs and strengths of employees on the autism spectrum.

- The DBHDID collaborates with the Kentucky Employment First Council, Office of Vocational Rehabilitation, UK HDI, and the Office of Autism on employment initiatives. These initiatives are dedicated to customized employment opportunities for individuals with disabilities who have a desire to work in the community but heretofore have not had opportunities to do so.

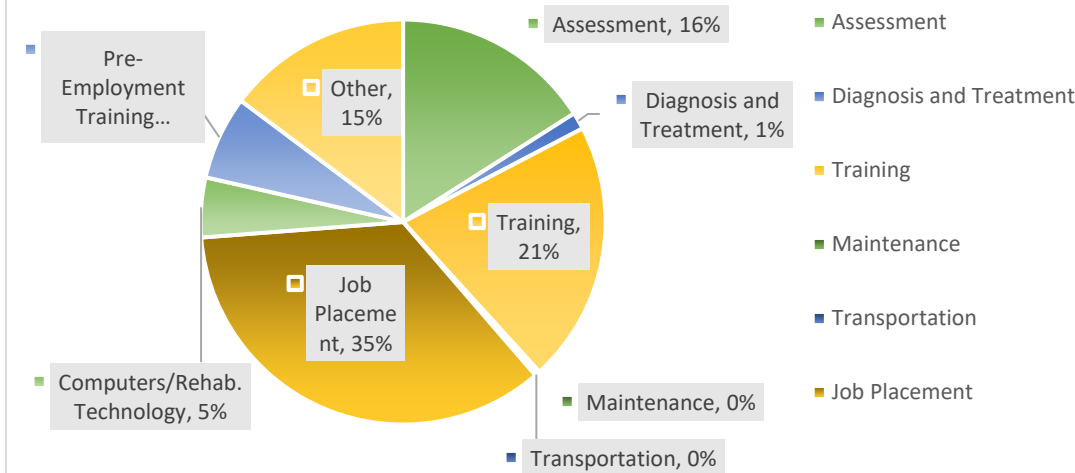
Office of Vocational Rehabilitation (OVR)

In State Fiscal Year 2022, the Kentucky Office of Vocational Rehabilitation (OVR) reported serving 1,684 individuals with autism with the majority, (73.5% or 1,238 individuals) being transition age youth (ages 16-24). This number shows an increase of individuals (536 or 47%) from those served in Fiscal Year 2020. Eighty-nine percent (89%) of individuals report their race as white, 8% black and the other 3% spread across Alaskan, Asian, or Hawaiian. Additionally, 8% identify their ethnicity as Hispanic or Latino. For Fiscal Year 2022, expenditures were \$2,685,471. The table below shares data for Fiscal Years 2021 and 2022 and so far in SFY 2023, including the total amount spent on these consumers with ASD, along with the percentage breakdown of types of services.

Since 2014, the Workforce Innovation and Opportunity Act requires Vocational Rehabilitation to set aside at least 15% of its federal funding to provide Pre-Employment Transition Services (Pre-ETS) to students with disabilities who are eligible or potentially eligible for VR services. The vast majority of students receiving pre-ETS begin as potentially eligible and have not yet applied, been accepted, or have an Individualized Plan for Employment with OVR. The services are available starting at age 14 and consist of five categories that include counseling on post-secondary education opportunities, instruction in self-advocacy, job exploration counseling, work-based learning experiences and workplace readiness training. OVR provided pre-ETS to 3,219 potentially eligible students in Fiscal Year 2022, with at least 47 reporting Autism as their disability (*it is not a requirement to report disability to receive Pre-ETS as a potentially eligible student*). The agency spent \$3,042,833 on these services with at least \$34,167 going to serve those potentially eligible students that reported Autism as their disability.

OVR partners with the Office of Autism, Kentucky Autism Training Center, and the University of Kentucky Human Development Institute. These partners work together to provide training and resources for parents, self-advocates, and professionals. OVR serves on the Advisory Council on Autism. The agency continues work to improve vocational rehabilitation outreach and services to persons with autism, both through regular services and Pre-Employment Training Services. OVR values the partnership with the Office of Autism and the Advisory Council on Autism for helping to share resources and shape current and future opportunities for individuals with autism.

SFY 2022 case expenditures for autistics



Office for Children with Special Health Care Needs (OCSHCN)

The Office for Children with Special Health Care Needs (OCSHCN) is a Title V agency that is part of Kentucky's Cabinet for Health and Family Services. OCSHCN offers regional pediatric specialty clinics, care coordination, early intervention services, early hearing detection and intervention and family support programs. Below are OCSHCN services and activities related to Autism.

Kentucky Autism Initiative in Treatment, Training, and Research (KAITTR) Collaborative, initiated in 2014, continues between the University of Louisville, University of Kentucky, Eastern Kentucky University, Western Kentucky University, the Kentucky Autism Training Center, and OCSHCN. KAITTR focus on five regional autism clinics where, to date, over 1,300 children, adolescents, and their families have received diagnostic services, medical consultation, and/or educational consultation services through clinics in Somerset, Bowling Green, Morehead, Owensboro and Paducah. Diagnostic evaluation is completed by a team of professionals from various backgrounds, each with specialized knowledge, training, and experience in working with individuals with Autism and other developmental disabilities and their families. The team includes child neurology, child psychiatry, developmental pediatrics, nutrition, speech therapy, social work and education specialists in a single multidisciplinary visit. Follow-up medical consultation and management is provided to over 600 children with a confirmed autism diagnosis by a neurologist, psychiatrist, and developmental pediatrician with specialized training in Autism. OCSHCN expert nurse care coordinators help facilitate managing medication, behavioral and educational needs, while also connecting families to local resource networks and regional providers. Importantly, these services are provided in a family-centered, Autism-friendly environment.

Extension for Community Health Care Outcomes (ECHO) Autism

ECHO Autism equips primary care providers to better care for their Autistic patients through a monthly virtual education presentation. ECHO Autism links learners to Autism specialists and provides valuable recommendations about diagnosis, treatment, and management of associated symptoms. The **Office of Autism** assists in the promotion of the ECHO program.

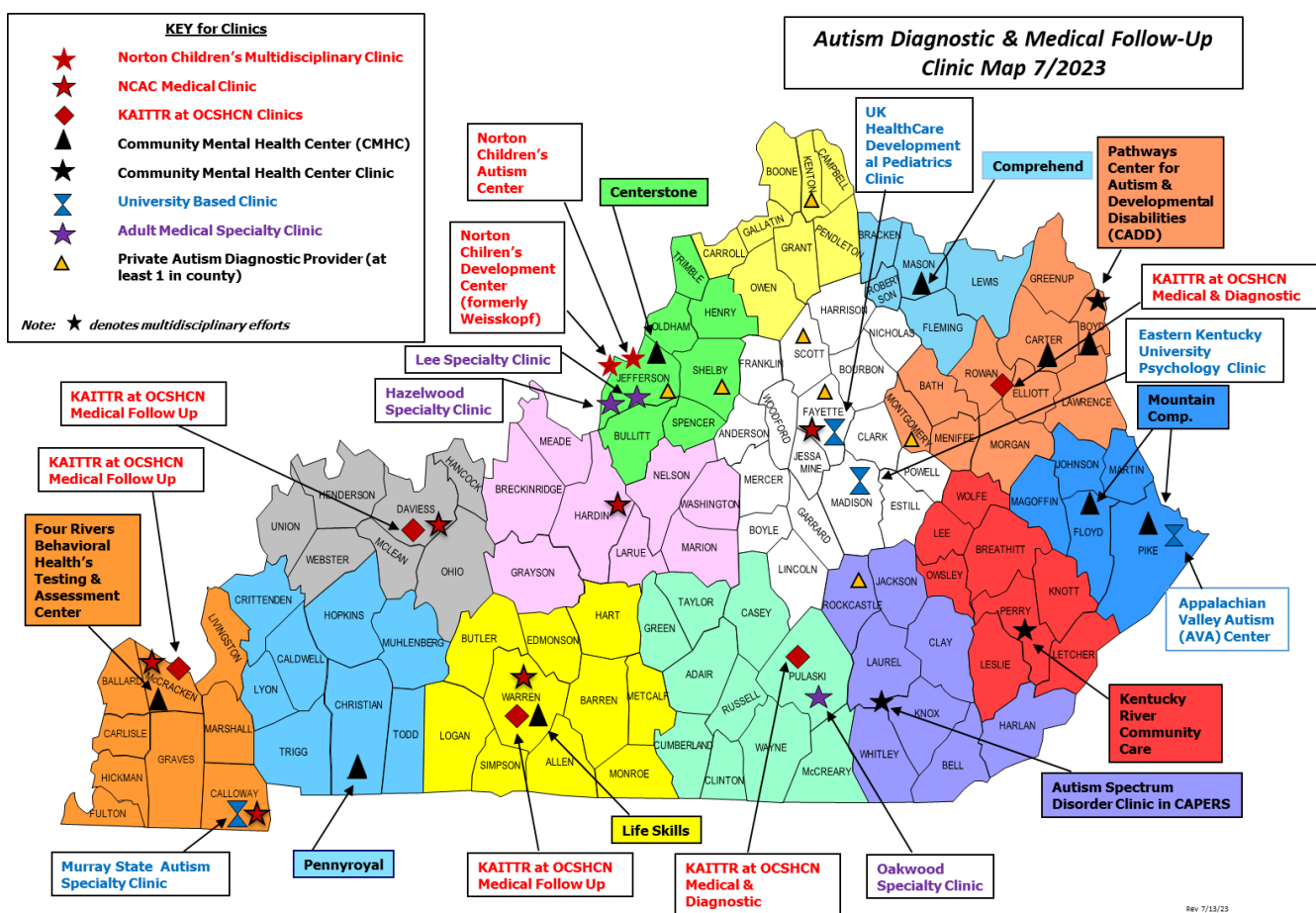
Equity Specific to Autism

OCSHCN's Equity Team shares information with staff through weekly emails. During this reporting period, the team included the following Autism related topics: the history of Autism Awareness Month, disparities in diagnosis and services, podcast from Autism Speaks on transitions, the prevalence of Autism in Kentucky and celebrating Autistic Joy.

OCSHCN and Office of Autism Collaboration

- The **Office of Autism** shares a multitude of information about Autism programs and services across the Commonwealth. The availability of the information allows OCSHCN care coordinators to guide families and make referrals to appropriate services.
- The **Office of Autism** advocated having diagnostic testing covered by insurance – thereby, increasing the number of children with access to testing. This increased the number of families able to receive services from OCSHCN.
- OCSHCN's leadership and care coordinators are active participants in the **Autism Diagnostic and Medical Follow-Up Collaborative Community of Practice** (See Figure 1). This group has proven to be an essential element in the direct sharing of information and resources between stakeholders across the Commonwealth. This is vital knowledge when serving autistics and their families. OCSHCN's Division Director for Clinical and Augmentative Services participated in the **Autism Community of Practice - Family Support and Case Management**.

Figure 1- Autism Diagnostic, Medical Follow-Up, & Treatment Clinics Collaborative (CoP) Map



Department for Community Based Services

According to Medicaid and pharmacy claims, in the 12-month period ending June 30, 2022, the Department for Community Based Services (DCBS) had served 974 (11.0% of total) children with autism spectrum disorder (ASD). Analyses of gender, race and ethnicity revealed 679 (69.7%) were male and 626 (64.3%) were White, 46 (4.7%) were Black, 16 (1.6%) were Hispanic, and 302 (31.0%) were Other.

This population is a complex group with multiple medical and emotional needs. ADHD (N=510, 52.3%), anxiety disorders (N=335, 34.4%) and PTSD (N=298, 30.6%) were frequent comorbid psychiatric diagnoses.

Of this group, 677 (69.5%) were treated with psychotropic medications. The most common classes of medications used in this population were alpha-agonists (N=484, 71.5%) and antipsychotic medications (N=451, 66.6%).

The following information is from the Children's Review Program for children who have required evaluation of their clinical needs to obtain a level for payment. This data will not capture children still with families or in DCBS foster homes. As of June 19, 2023, there were 397 children currently in DCBS custody with a diagnosis of autism spectrum disorder with a history of autistic disorder. Of these 397 children, 165 were in private child-placing agency foster homes, 72 were in private child-caring residential treatment facilities, and 25 were in DCBS foster homes. In addition, 32 were placed with a Support for Community Living provider, 22 were in acute psychiatric hospitals, 19 were in Independent Living Programs, 12 were placed in out-of-state residential, and six were in an intermediate care facility. Thirty-five were in a parent, relative or fictive kin placement. The remaining eight were in temporary programs such as detention, a crisis stabilization placement, or an emergency shelter.

Table - Children in DCBS custody with ASD range from 4 years to 20 years of age.

Age of child (years)	Number of children in DCBS custody
0 to 5 years	30
6 to 11 years	103
12 to 17 years	192
18 to 21 years	72

Children with ASD have unique needs which can be difficult to meet. DCBS has partnered with Key Assets to develop the Children in Community Care (CCC) Program to provide a continuum of care for youth and young adults who have mental health diagnoses such as autism spectrum disorders and Developmental and Intellectual Disabilities and who are placed in the custody of the Cabinet for Health and Family Services. These youth live in Key Assets group homes and have complex needs that require an intensive, therapeutic placement option.

DCBS has developed a Clinical Branch within the Division of Protection and Permanency with enhanced clinical capacity to identify and serve the needs of children in foster care with medical and emotional/behavioral needs including those with autism spectrum disorders.

Since Jan. 1, 2021, DCBS has been served by a single Managed Care Organization, Aetna SKY, which features focused case management and quality activities to serve children with complex needs such as autism spectrum disorders. In addition, beginning in May 2021 DCBS hired regional Nurse Clinical Investigators formerly employed by the Office for Children with Special Health Care Needs to increase medical capacity in the regions. These nurses will work with medically complex children and children and provide additional support for psychotropic medication monitoring.

Kentucky Protection & Advocacy (P&A)

Kentucky Protection & Advocacy (P&A) is a state legal rights agency that protects and promotes the rights of individuals with disabilities and those who are deaf and hard of hearing. P&A's advocacy efforts include the protection of individuals from abuse and neglect as well as legally based advocacy to protect and promote the civil rights of individuals with disabilities through technical assistance, information and referral services, individual representation, and systemic advocacy. P&A serves individuals of all ages and cross-disability and individuals who are deaf/hard of hearing. P&A is a client-directed agency, meaning the individual with a disability or who is deaf or hard of hearing is the client and that case direction is taken directly from that individual.

Following the end of the COVID quarantine, P&A's staff are back in the office, but more importantly have returned to and are maintaining a presence in institutions and facilities and meeting face-to-face with clients. The creativity and flexibility developed using technology during the pandemic broadened the agency's reach and P&A will continue to use technology to advocate for and serve clients.

P&A advocates and attorneys provide individual representation across the state on a wide array of issues. During the 2021-22 fiscal year, P&A provided services to 2,135 individuals through individual advocacy, including information and referral, technical assistance, and individual representation. Of that number, 286 (13%) were specifically identified as being on the autism spectrum or having a pervasive developmental disability. P&A assisted clients with autism on a variety of issues, including investigating allegations of institutional abuse; obtaining a free and appropriate education; access issues; housing, employment and transition services; and obtaining appropriate healthcare services. P&A also advocated for systemic change at both the state and federal level. P&A systemic advocacy efforts included activities such as commenting on proposed state and federal legislation; participating on state boards and councils like State Interagency Council subcommittees, the Kentucky Advisory Council on Autism, and the Kentucky Interagency Transition Council and staffing a voter hotline on election days.

Kentucky Department of Juvenile Justice (DJJ)

The Kentucky Department of Juvenile Justice (DJJ) provides a range of services to sentenced, committed, probated, and detained youth and their families, creating opportunities for those youth to develop into productive, responsible citizens while enhancing public safety. DJJ continues to strive to improve services to youth in care that fall on the autism spectrum, developmentally delayed, or learning-disabled youth and their families. Treatment is based on evidence-based practices and are tailored to meet the needs of each individual. DJJ has a representative serving as a gubernatorial appointee to the Kentucky Advisory Council on Autism and serves on the adolescent and adult subcommittee as well.

The Arc of Kentucky

The Arc of Kentucky (The Arc) is a statewide grassroots advocacy organization that works to ensure a quality life for children and adults with intellectual and developmental disabilities. The Arc holds a vision of a positive future for individuals with intellectual and developmental disabilities and a future of communities with services and supports that will promote lives of value for Kentuckians with intellectual and developmental disabilities.

Due to the difficulties faced in the pandemic, The Arc's activities/events/programs were postponed throughout the year and have yet to be restored. This includes the Wings for Autism Program sponsored by The Arc of the U.S. and The Arc of Kentucky at the Louisville and Lexington Airports, the Kentucky Advocates in Action Training Program, the Annual Statewide Best Practices Conference, etc. The Arc's programs, trainings etc. are currently being revisited and reorganized. In the meantime, The Arc continues to advocate for the Kentucky Legislature to increase the number of slots in both the Support for Community Living (SCL) and Michelle P. Waiver (MPW) programs to decrease the waiting list in both programs. The Arc of Kentucky continues to advocate for the full inclusion and participation in the community throughout their lifetime.

The Arc of Kentucky's Self-Empowerment Network which serves individuals with disabilities including autism continues to meet and actively address issues such as improving community access, housing opportunities, transportation, employment opportunities, education, supported decision making, etc.

Commonwealth Council on Developmental Disabilities

The Commonwealth Council on Developmental Disabilities (CCDD) mission is to create systemic change in the Commonwealth of Kentucky, empowering people with developmental disabilities to achieve full citizenship and inclusion in the community through advocacy, capacity building, and systemic change. CCDD envisions

communities that fully engage, support, and provide equal opportunity for every person to be valued and a contributing member in their community.

CCDD is governed by the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) of 2000 DD Councils are funded through the federal appropriations process. Specifically, they are allocated funding through the Administration on Intellectual and Developmental Disabilities under the US Department of Health and Human Services. CCDD has one representative that is appointed to the KYACA. This is the parent of someone who is autistic. CCDD also has one staff person who attends all KYACA meetings and serves on a subcommittee.

CCDD funds projects throughout the state that help to address the goals of our 5-year plan. Current projects that impact that autistic community are as follows:

Kentucky Partners in Policymaking

The goal of Kentucky Partners in Policymaking (KPIP) is to accomplish productive partnerships between the people needing and utilizing services and those who form public policy. KPIP was founded on the belief that the most significant and lasting public policy decisions came from the efforts of those most affected by them, working together with public officials and policy experts. KPIP educates participants about present issues and best practices and teaches them about local, state, and federal levels legislative processes of policymaking.

Transportation Initiative

The Transportation Initiative is a CCDD funded project with the University of Kentucky's Human Development Institute (UK HDI). The Transportation Initiative seeks to provide comprehensive information and education on transportation options. Training materials including video, audio, and print material may be found at the Transportation Initiative website. Topics include Americans with Disabilities Act (ADA) Paratransit, Non-Emergency Medical Transportation (NEMT), Hart-Supported Living, Ride Share, Blind Work Expense, K-TAP Kentucky Works Program, etc.

My Choice Kentucky: Supported Decision-Making

Supported decision-making is the use of trusted friends, family members, and professionals to get the help needed to make one's own decisions. This project is a partnership between CCDD, UK HDI and Protection and Advocacy. UK HDI staff provides training on supported decision making to interested parties.

Housing Solutions Projects

CCDD has provided funding to Mattingly Edge to take on the challenge of identifying current housing issues in Kentucky for people with disabilities and providing a road map for addressing those challenges. The research and work will focus on creating typical housing options for people with disabilities that are integrated and desirable to the average citizen. The Housing Solutions Project seeks to provide a variety of solutions to this issue, including homeownership, multi-family housing, co-housing with non-disabled peers, community land trusts and tenancy.

DiscoverU Kentucky is the self-advocacy initiative that CCDD funds in compliance with the DD Act.

DiscoverU aims to create systemic change in the Commonwealth that empowers people with disabilities to achieve a sense of belonging, full citizenship and inclusion in the community. Often, individuals with disabilities, their families/guardians, and others in their lives face challenges obtaining information regarding resources, access to care, peer groups, etc. DiscoverU Kentucky's purpose is to empower, educate and advocate collectively. The efforts are multifaceted, but in its simplest form, DiscoverU Kentucky shall support and encourage community stakeholders to come together, provide links to readily available resources and remove siloed information and assist individuals, families/guardians navigate their disability journey.

Edge Employment seeks to increase Competitive Integrated Employment for students who have a disability transitioning out of high school by sharing information that demystifies the fear of losing disability benefits.

They strive to do this through JCPS high school presentations that show the financial and social benefits of working, the real (limited) impact on disability benefits, and that inspire allies to bring these issues to their own personal and professional spaces. Allies will have the opportunity to serve as Disability Employment Ambassadors alongside Edge Employment, creating new opportunities for inclusive employment.

Exceptional Family Kentucky is the only magazine dedicated to disability issues in Kentucky. It is published twice per year and distributed statewide: 20,000 copies are printed in English and 2,000 in Spanish. The resource guide boasts over 450 listings.

Kentucky Telehealth Law Update

During the COVID pandemic, Kentucky's Division of Telehealth and its Steering Committee and work groups worked tirelessly with licensure groups across the Commonwealth to ensure that all persons requiring health care, including wellness care, could receive that care via telehealth where appropriate. Working from the strong legislation passed by the state Legislature in 2021, the Commonwealth rose from the bottom of the ranks of states in the nation using telehealth to the top 10.

During the past year (2022-2023), the Division of Telehealth was moved to be housed under the Office of Inspector General and most of the advances made in 2021 have been eroded by a two-year Executive Branch "suspension" of most governmental telehealth activities. Kentucky is currently ranked in the bottom 10 states for telehealth advancements and support. That low ranking reduces the ability of certain patients to access care via telehealth that is insurance paid, particularly from specialists and providers out of state. In recognition of this, many out of state telehealth providers allow cash pay services and many private insurance companies (and even Medicare, in some cases) encourage use of their proprietary and free telehealth services. Kentucky Medicaid and the Kentucky Department of Insurance provide reimbursement for providers who use telehealth in accordance with applicable administrative regulations.

Having access to telehealth care is vital to the community of autistics and their families and caregivers. Reducing the fear, uncertainty or overwhelming stimuli associated with healthcare service provision is key to ensuring that autistic people can regularly obtain the healthcare they need. Telemedicine can also reduce anxiety in persons who can control that by choosing the method of contact with the health care provider. Persons who do not communicate verbally can use a video encounter along with writing or typing questions and answers to effectively access therapies or treatment.

Telehealth settings can include Federally qualified health centers, school telehealth, post-acute and long-term care facilities, rural hospitals, primary care, dental care, eye care, chiropractic care. Use of telehealth requires patient consent, either written or verbal. KRS 311.5975. Patients can give that consent during a telehealth visit, so that this consent becomes part of the patient record.

While the state has rendered its Kentucky Division of Telehealth Services, the Kentucky Telehealth Steering Committee, and the state website "inactive," there are various entities and organizations in the state who can advise and guide persons with questions about telehealth. These include many Kentucky Rural Health Clinics and FQHC hospitals, licensure boards, and local or regional advocacy groups.