



Biennial Report of the Kentucky Advisory Council on Autism

Sept. 30, 2021

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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. 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*. (For more information on social model of disability, see page 5 of this report)

AUTISM PREVALENCE

In March 2020, 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 54** births in the United States (1.85% of the population). (CDC, March 2020):

<https://www.cdc.gov/ncbddd/autism/data.html>

Table 1 - Autism Estimates Applied to KY Census Data from July 2019

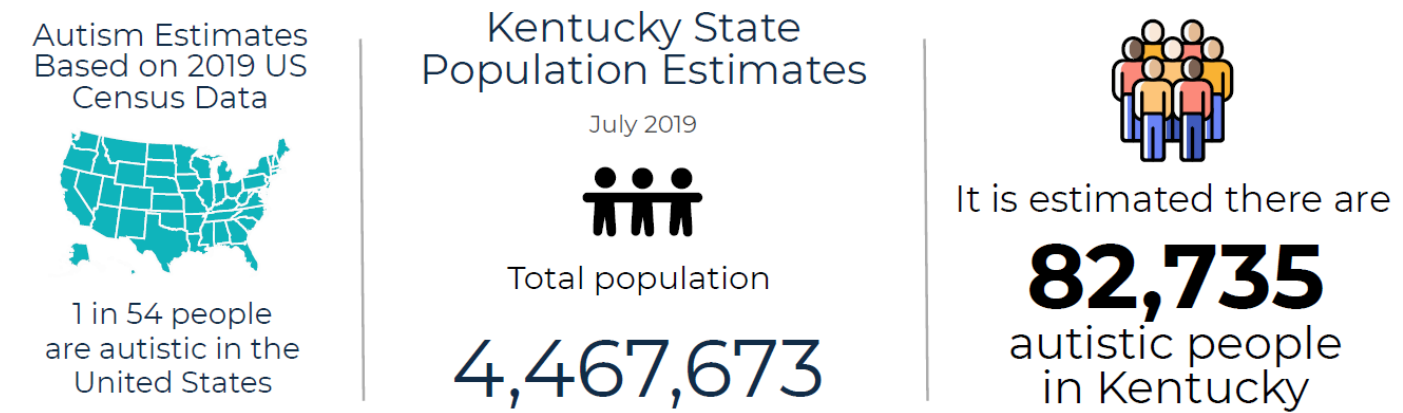
Population Statistics	KY Population (7/2019)	Applied Autism Estimates based on 1 in 54
Kentucky State Population estimates, July 1, 2019	4,467,673	82,734
Persons under 5 years is 6.2%	276,996	5,130
Persons under 18 years is 22.6%	1,009,694	18,698
Persons 65 years and over is 16.4%	732,698	13,568
Race		
White alone 87.6%	3,913,682	72,476
Black or African American alone 8.4%	375,285	6,950
American Indian and Alaska Native alone, 0.3%	13,403	248
Asian alone, 1.6%	71,483	1,324
Native Hawaiian and Other Pacific Islander alone, 0.1%	4,478	83
Two or More Races, 2.0%	89,353	1,655
Hispanic or Latino 3.8%	169,772	3,144
White alone, not Hispanic or Latino, 84.3%	3,766,248	69,745

Source: Data from U.S. Census Bureau at <https://www.census.gov/quickfacts/fact/table/KY/PST045218>

Kentucky Autism Prevalence Infographic

Through collaboration and research, the KYACA created the October 2020 Report: Kentucky Autism Prevalence Infographic. The purpose of this infographic is to promote awareness about national autism prevalence rates and to apply these national rates to the Kentucky population, highlighting an increase in current autism rates. The national estimated rate for Autism is about 1 in 54 or 1.85% of a national sample of 8-year-olds. This prevalence is higher than that of the previous report in 2018, which found an autism prevalence of 1.7%, or 1 in 59. Of course, these are *estimated* prevalence rates, and the rates of actual identification of children and adults are lower, and reflect a need to redouble our efforts to ensure that all individuals with autism have the opportunity for accurate screening and diagnosis. (See Table 2 on p.3)

Table 2 - Section of Kentucky Autism Prevalence Infographic below



Source: <https://www.kyaca.org/2021/04/12/autism-prevalence-in-kentucky-infographic/>

To see Kentucky autism prevalence estimates by County, see this [link](#).

Adult Prevalence

- An estimated 5,437,988 (2.21%) adults in the United States have ASD. A study from the Centers for Disease Control and Prevention (CDC) estimated the prevalence of autism spectrum disorder (ASD) among adults aged 18 years and older in the United States in 2017*. This study fills a gap in data on adults living with ASD in the United States because there is not an existing surveillance system to collect this information.
- Consistent with estimates of ASD in US school-aged children, prevalence was found to be higher in men than in women.
- Approximately 4,357,667 (3.62%) male adults were estimated to have ASD, with state estimates ranging from 3.17% of men in South Dakota to 4.01% of men in Massachusetts.
- Approximately 1,080,322 (0.86%) female adults were estimated to have ASD, with state estimates ranging from 0.72% of women in Arkansas to 0.97% of women in Virginia.
- ASD is a lifelong condition, and many adults with ASD need ongoing services and supports. The findings from this study can help states determine the need for diagnosing and providing services to adults in the United States who remain unidentified with ASD.

Note: Estimates were based on modeling inputs from state-based population and mortality data and parent-report survey data of US children diagnosed with ASD.

Source: <https://www.cdc.gov/ncbddd/autism/features/adults-living-with-autism-spectrum-disorder.html>

Autism National Facts & Statistics

- Prevalence of autism in U.S. children increased by 119.4 % from 2000 (1 in 150) to 2010 (1 in 68) (CDC, 2014). Prevalence has increased by 6-15% each year from 2002 to 2010 (based on biennial numbers from the CDC).
- Autism services cost U.S. citizens \$236 - \$262 billion annually (Buescher et al., 2014).
- A majority of costs in the U.S. are in adult services – \$175 - \$196 billion, compared to \$61 - \$66 billion for children (Buescher et al., 2014).
- In 10 years, the annual cost will be \$200-400 billion (Autism Society estimate).
- Cost of lifelong care can be reduced by 2/3 with early diagnosis and intervention (Autism Society estimate based on Government Accounting Office Report on Autism, 2007).
- It costs more than \$8,600 extra per year to educate a student with autism (Lavelle et al., 2014). (The average cost of educating a student is about \$12,000 – NCES, 2014).
- The U.S. cost of autism over the lifespan is about \$2.4 million for a person with an intellectual disability, or \$1.4 million for a person without intellectual disability. (Buescher et al., 2014)

- 35% of young adults (ages 19 - 23) with autism have not had a job or received postgraduate education after leaving high school. (Shattuck et al., 2012)

Source: <https://www.autism-society.org/what-is/facts-and-statistics/> (8/26/2015)

KENTUCKY OFFICE OF AUTISM

As a part of the Cabinet for Health and Family Services, Department of Behavioral Health Developmental and Intellectual Disabilities, the Office of Autism is housed at the Cabinet for Health and Family Services with additional offices at the University of Kentucky Human Development Institute and the University of Louisville Autism Center to provide ample opportunity for collaboration and access. The office coordinates statewide efforts to enhance the quality of life and independence for individuals with an autism spectrum disorder 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. Specifically, the office is charged to:

- Create a centralized location to coordinate statewide and regional efforts to enhance the quality of life and independence for individuals with an autism spectrum disorder and to support their families and caregivers;
- Improve coordination of autism resources within the systems of care supporting children and adults with autism and help make those resources available to families and self-advocates; and
- Provide administrative support to the Advisory Council on Autism. Coordinate subcommittee meetings and project initiatives. Schedule and prepare quarterly meetings including Executive Committee conference calls. Assist with inquiries by KYACA members and staff. (See Table 3 for further details.)

Additional information can be found at the website <http://www.kyaca.org/>.

Table 3 - Office of Autism Completed Outcomes

Office of Autism Goals (chart represents goals from KRS 194A.623)	Completed Outcomes 7/2020 to 6/2021
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	84 Unduplicated new constituent concerns addressed 43 Professional (not KYACA members) inquiries addressed 75 Parent/Family/Self-Advocate inquiries addressed 12 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	8 Presentations 19 Committees 7 Public events 2 Visits to diagnostic or medical clinics 15,015 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 in Table 5. • Schedule and prepare for quarterly meetings, including executive committee conference call. • Respond to inquiries by KYACA members & staff. • Coordinate 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 in July 2014 amended the original order and 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. Council meetings are open to the public and allow citizen input. The joint mission of the KYACA and the Office of Autism is to promote collaborative efforts and advocates to improve system of supports for autistics. 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. The Office of Autism links these partners together and provides a centralized location to ensure that Kentucky remains a national leader in the field.

KYACA has sought to be inclusive of self-advocates and has broadened the Council's collective understanding of autism to include three perspectives of autism below:

- The **medical model** describes autism as a life-long developmental disability, resulting from neurological differences that affect brain functioning in areas of socialization, communication, and interests/behavior. For a full criteria list, [DSM 5 definition of autism spectrum disorder](#)
- The **educational model** describes autism in terms of the negative impact on learning in a school setting. The educational model is defined federally within educational eligibility criteria for an Individual Education Plan (IEP), which focuses not on a diagnosis but on how symptomology impedes a student's ability to learn. The primary areas of focus include communication/language skills, social interaction, repetitive behaviors and restricted interests. More information [Kentucky Education Autism Guidance Document](#)
- The **social model of disability** focuses on strengths and accepting neurological differences as a positive part of a person. Many autistic self-advocates support the neurodiversity paradigm, which is closely related to the [social model of disability](#), that views disability as caused by the way society is organized, rather than by a person's impairment or difference. It looks at ways of removing barriers that restrict life choices for disabled people. Autism and other disabilities are viewed as naturally occurring variations, which should be respected and supported through accommodations and understanding.

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 autistic's definition of autism, ensure meetings are more accessible through resources like [ISAW Meeting Accessibility tools](#), and expand the representation on the Council to include more persons with autism. Finally, KYACA is working toward greater inclusivity by honoring self-advocates motto "[nothing about us, without us](#)." This continues to be an area of ongoing growth for the Council and representatives we must continue to recognize and work on. This ongoing growth is reflected in the addition of "autistics" in the mission and vision below.

KYACA Mission and Vision

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

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

KYACA Membership

The co-chairs of the Kentucky Advisory Council on Autism (KYACA) are Governor-appointed and represent the University of Kentucky, Dr. Kathy Sheppard-Jones, and the University of Louisville, Dr. Gregory Barnes. (See link for [KRS 194A.624](#) for more information on membership requirements)

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 SUBCOMMITTEES

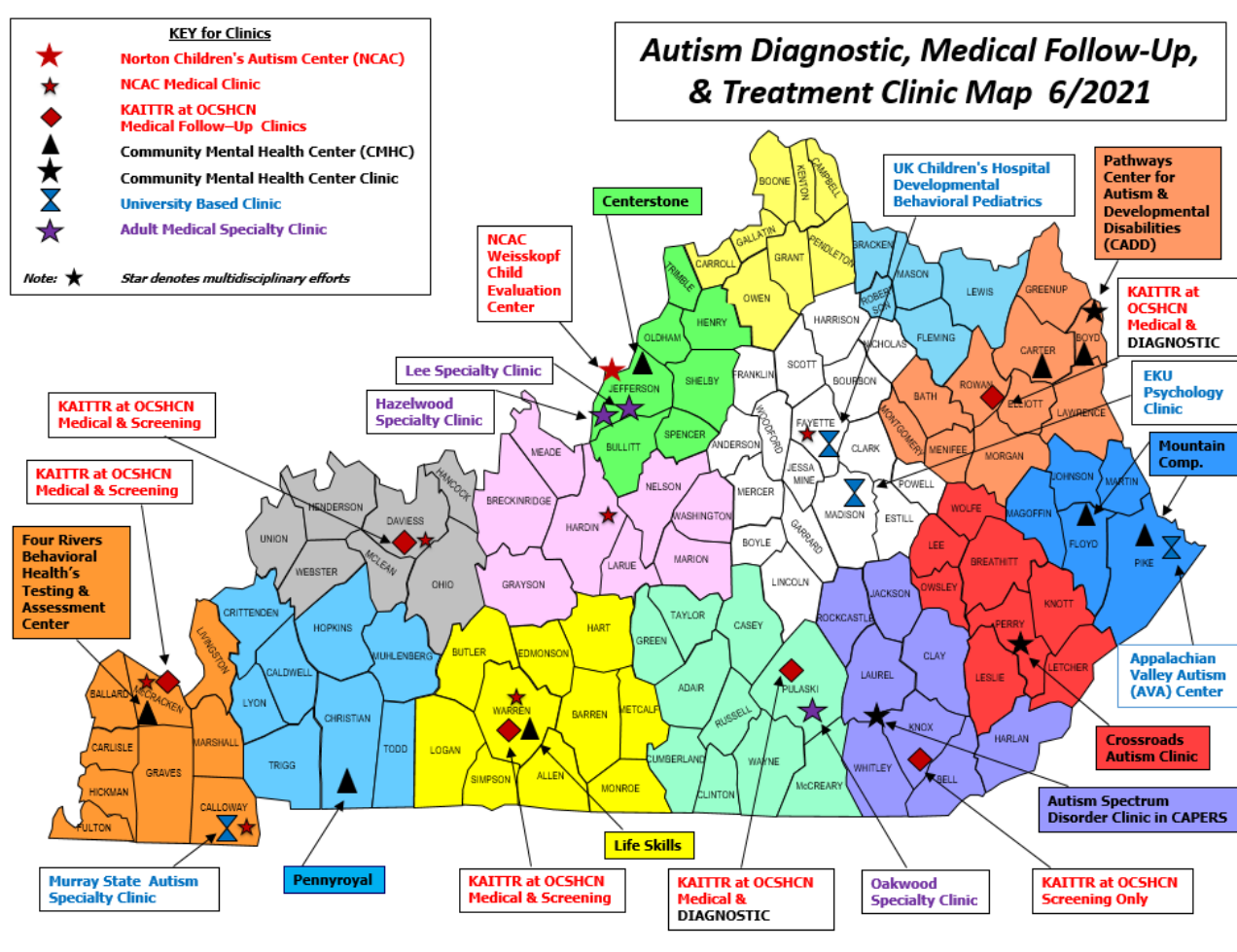
Early Childhood Subcommittee

The 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 (5). (See Table 5 for additional project information.)

Completed Tasks

- Created online [Autism 101 for Early Childhood Providers](#).
- Created online [KYACA Orientation overview](#) to assist new members, agencies, and partners
- Continued Autism Connect the Dots Dissemination with first training of new curriculum held March 4-5, 2020. Due to pandemic, postponed further in person trainings and created online modules.
- Updated KYACA webpage [Resources for Infant and Toddler \(0-3\)](#)
- Created Autism Diagnostic, Medical Follow-Up, & Treatment Clinics Collaborative Community of Practice in March 2021, to increase networking and communication among partners (See Map below).

Table 4 - Autism Diagnostic, Medical Follow-Up, & Treatment Clinics Collaborative (CoP) Map



Early Childhood Subcommittee Ongoing Discussion

- OCSHCN Medical Follow-Up & Diagnostic updates
- Short-term and long-term impact of pandemic
- Racial Equity Discussions as permanent meeting agenda item.
- Diagnostic training opportunities like ADOS-2 training from Kentucky Autism Training Center
- Center for Disease Control (CDC) Act Early Ambassador Updates
- Telehealth discussions and updates (See p. 26 for Telehealth Law Update)

School Age Subcommittee

The School-Age Subcommittee's work involves the consideration of issues related to the lives of children and young adults ages five (5) 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 (individuals with autism). (See Table 5 for additional project information.)

Completed Tasks

- Created Autism Training Matrix - to embed unified training in other state agencies & serve as a tool for autism resource dissemination and collaboration.
- Updated KYACA webpage [Resources for Children 3-14](#)
- Continued Parent Summit. (As a project of the KYACA, see p.11 under Parent Summit)
- Established a committee comprised of educators, parents, and autistics to address Language Awareness & Diversity Task. One goal of committee to identify replacement language for the existing functional labels used to categorized (and often limit) individuals with autism (autistics). Combined efforts with Adolescent & Adult Subcommittee to present Social Model of Disability to administrative educators in an effort to create "culture shift/change".

School Age Subcommittee Updates

- Racial Equity Discussions as permanent meeting agenda item.
- Telehealth discussions and updates
- Concerns with impact of pandemic on education/behavioral health became ongoing agenda item
- Diagnostic training opportunities like ADOS-2 training from Kentucky Autism Training Center
- Ongoing education and technical assistance to parents, educators, and other partners

Adolescent & Adult Subcommittee

The Adolescent and Adult Subcommittee's work has focused on improving services across the life span for autistics and understanding individuals' needs as they relate to transition from school into adult life and the strengths and challenges 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](#). (See Table 5 for additional project information.)

Completed Tasks

- Facilitated the *Autism Transition Summit: Focus on Employment on March 10-12, 2020* at Marriot Louisville East.
- Continued collaboration with Innovative Supports for Autistic Workers (ISAW) Project (As a project of the KYACA, see p. 9 of this report for detail of ISAW)
- Continued education presentations by self-advocates to subcommittee including "Including autistic people in meetings", 4/28/20, "Social Model of Disability", 10/23/20, and "Defining Autism", 4/30/21.
- Continued growth in ensuring that the meetings are more [accessible](#) and work towards inclusion in terms of verbal, written, and other methods of communication, meeting modalities that are as inclusive as possible, and fostering the "[nothing about us, without us](#)."
- Updated KYACA webpage [Resources Adolescents \(14-21\)](#) and [Resources Adults \(21+\)](#)

- Developed [Autism Prevalence Infographic October 2020](#) and assisted with demographic survey for use with Council and subcommittees.
- Participated in KentuckyWorks project activities including development of [Kentucky Checklists for a Bright Future](#), which include a total of eight (8) one-page checklist of the most important things parents and youth can do to prepare for meaningful employment and financial security at each age.

Adolescent & Adult Subcommittee Updates

- Employment First Council
- KentuckyWorks
- Adult Diagnosis options and began list of providers for subcommittee to update.
- Autism Housing/Independent Living Update –Alternative housing presentation shared.
- Racial Equity Discussions as permanent meeting agenda item.
- Violence against autistics including discussion about law enforcement brutality and abuse, school related challenges, and models for change and hope. Discussion and possible tasks ongoing.

KYACA PROJECTS FY 2020-2021

The following table consists of the major KYACA projects.

Table 5 - KYACA PROJECTS FY 2020-2021

FY20-21 Projects (Subcommittee)	Target Audience	Objective	Timeframe/Notes	Key Partners
Innovative Supports for Autistic Workers (ISAW) Project (Adolescent & Adult)	Business Service Teams, Supported Employment Specialists, OVR, Employers, & Autistics	Increase # of autistic employees in competitive jobs through training and technical assistance	<ul style="list-style-type: none"> Continued creation of relevant tools including online modules and downloadable print materials 	OVR, UK HDI, Self-Advocates, Office of Autism
Autism Transition Summit (Adolescent & Adult)	Transition Age Youth, Parents, Self-Advocates, & Professionals	Provide self-advocates, families, and professionals knowledge and skill opportunities across the lifespan	<ul style="list-style-type: none"> On March 10-12, 2020, hosted Transition Summit in Louisville, KY 	OVR, ULAC, KATC, DBHDID, UK HDI, Self-Advocates, Office of Autism
Connect the Dots Autism Dissemination Project (Early Childhood)	Family support leaders, state technical assistance and training professionals,	Provide training to family support leaders working with newly diagnosed families with autism with children through age 8.	<ul style="list-style-type: none"> On March 4-5, 2020, first training of new curriculum held Recorded online modules and plan to finalize access by Fall 2021 	Dept. or Public Health, KATC, U of L College of Education, DBHDID, Office of Autism
Racial Equity Plan (All three subcommittees)	KYACA and three subcommittees	KYACA and allies have had the racial/gender diversity training and are working to ensure that in all written materials, meetings and trainings, all members, volunteers and	<ul style="list-style-type: none"> Began in August 2020 Permanent Meeting agenda item in Nov. 2020 Goals and objectives aligned 	All Council

		vendors ensure equality, respect and cultural competency.	with Racial Equity Commitments across the subcommittees.	
Autism Prevalence Infographic <i>(Adolescent & Adult)</i>	KYACA and three subcommittees, public at large	The purpose of this infographic is to promote awareness about national autism prevalence rates and to apply these national rates to the KY population, highlighting an increase in current autism rates.	<ul style="list-style-type: none"> Included on website Autism Prevalence Infographic October 2020 	DPH, KDE, KATC, DBHDID, UK HDI, OVR, Office of Autism

KYACA EXPANDED PROJECT NARRATIVE FY 2020-2021

Innovative Supports for Autistic Workers (ISAW) Project

[Innovative Supports for Autistic Workers \(ISAW\)](#) was created through funding from the Kentucky Advisory Council on Autism and the KY Office of Vocational Rehabilitation in 2016 to support Business Service Teams (BST) within Kentucky Career Centers. A preliminary survey indicated very few BST leaders were confident in their abilities to support autistic job seekers; even fewer reported being comfortable with helping business managers understand their employees on the spectrum. During its first two years, ISAW focused primarily on delivering trainings and consultation to these Business Service Teams. While the teams were receptive, they also believed the ideal audience for ISAW trainings would be Human Resource managers. As a result, ISAW expanded its focus to include the Society of Human Resource Managers (SHRM) in 2018, and began more direct outreach to employers across the state.

For 2020-21, ISAW again expanded its offerings with outreach to all Kentucky Community Rehabilitation Partners (CRPs) and OVR staff. Trainings were redesigned to focus on the roles of employment specialists and support staff. ISAW delivered trainings for all CRP staff in February and June of 2021. These trainings have created demand for consultations with employment professionals across the state. ISAW staff regularly provide feedback and advice to agencies supporting autistic workers and job seekers. Several of these consultations have already resulted in new jobs for autistic job seekers. The project's next training for OVR staff is scheduled for July 2021.

ISAW continues to provide consultations directly to businesses in Kentucky and beyond. Most recently, the project has worked with Norton Healthcare in Louisville and with Toyotetsu in Somerset to create more accessible workplaces for new hires for additional staff training.

In addition to in-person and web-based trainings, ISAW provides print materials (fact sheets, brochures, posters, etc.) for use by businesses and employment specialists. The project's website hosts training modules on topics ranging from accessible interview techniques to sensory accommodations and more. New resources for 2020-21 include infographics on the effects of "masking" as neurotypical at work as well as modules and fact sheets on creating autistic-friendly workplace cultures.

ISAW staff provide direct assistance to job seekers by teaching interview skills, reviewing and editing resumes, counseling on topics such as disclosure and requesting accommodations, and connecting to additional resources. In 2020, ISAW served more than 10 individuals seeking work and provided long-term supports to four autistic workers facing ongoing employment struggles.

The project also disseminates information through conference presentations and other invited talks. Over the past two years, ISAW presented at Kentucky Association of People Supporting Employment First (APSE), The

Arc, Kentucky Rehabilitation Association, and the Up in KY conference. ISAW presentations were featured at APSE national conferences in 2020 and 2021. Provider agencies across the state have requested and received ISAW trainings for staff in Lexington, Louisville, Owensboro, and Somerset.

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 2020, ISAW interviewed six consultants about their experiences with employment during the pandemic; in 2021, eight new consultants shared their perspectives on unwritten rules in the workplace. Consultant stories are shared through ISAW's website and social media and are used to develop new trainings.

ISAW participates in all meetings of the Adolescent & Adult Subcommittee, sharing reports on employment related activities and collaborating on Council projects. ISAW staff have taken the lead on educating subcommittee members to better understand the needs of autistic adults in the workplace and self-advocates in general.

The project continues to grow through regular participation at SHRM meetings, the KentuckyWorks state advisory council, and the Bluegrass Coalition for Workforce Diversity. While the employment situation for autistic people in Kentucky remains bleak, ISAW is laying a foundation for greater understanding and acceptance among the state's employers. For more information, go to www.isaw.hdiuk.org

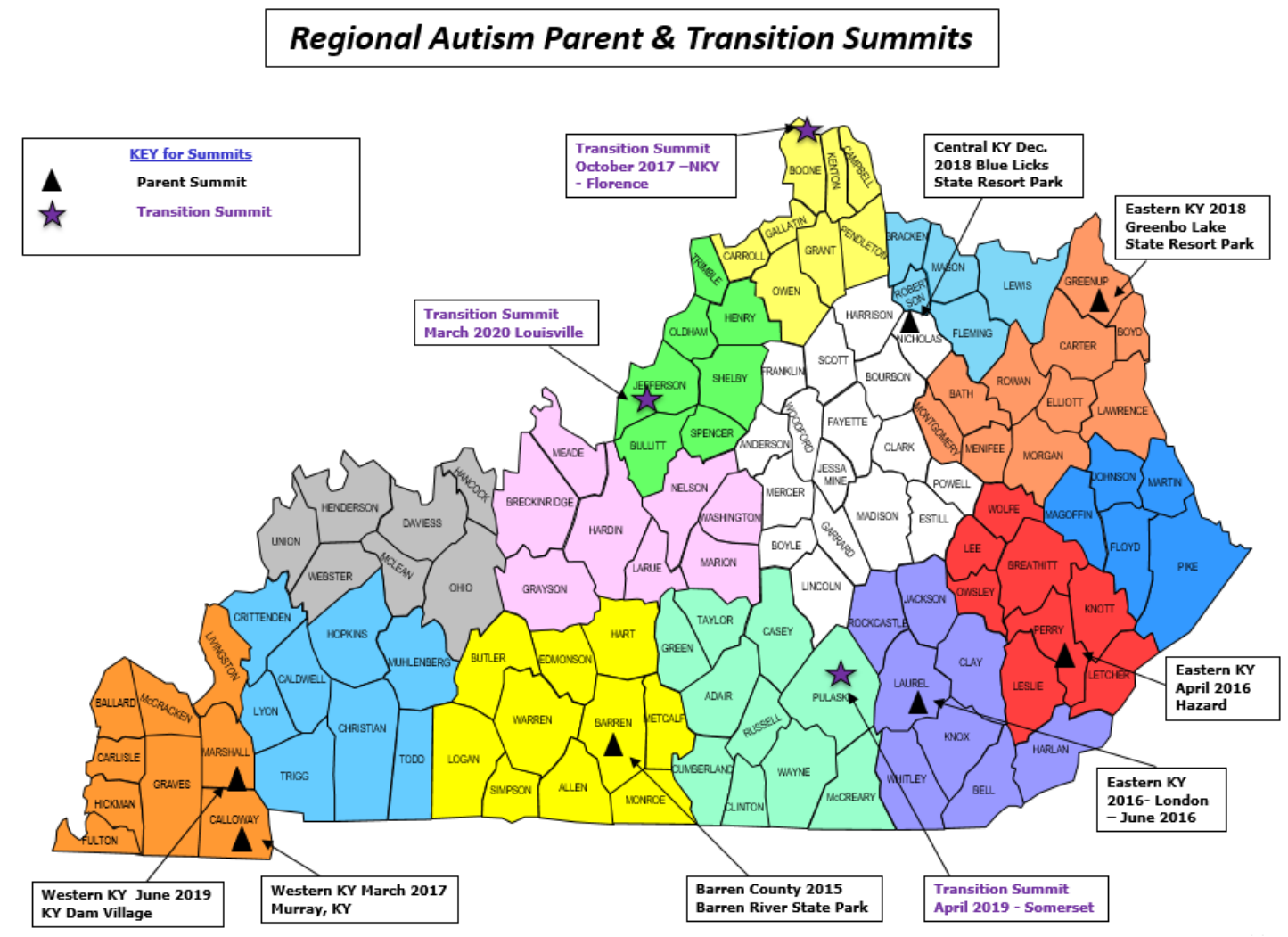
Autism Transition Summit

The Autism Transitions Summit: Focus on Employment was hosted at the Marriott Louisville East in Louisville, Kentucky, on March 10-12, 2020. This collaborative event was sponsored by the Kentucky Office of Autism, UK Human Development Institute, Kentucky Office of Vocational Rehabilitation, and Kentucky Autism Training Center and included partnerships across KYACA membership. The goal was to provide training to parents, self-advocates, caregivers, and professionals on supporting autistic people as they transition into employment. The planning committee worked hard to make this an inclusive and accessible event by setting expectations such as the freedom to move around during sessions, offering the use of communication badges (as a means to express current communication needs and/or preferences), encouraging flapping, rather than clapping, and offering a "chill room." The "chill room" was created for those in need of a break or quiet space during the summit and included meeting fidgets (stim toys), art supplies, noise cancelling headphones, beanbags, weighted blankets, and other self-care items. The Summit sessions were conducted by self-advocates and professionals.

Parent Summits

The goal of the Parent Summits is to provide parents, caregivers, and self-advocates the opportunity to obtain information on statewide resources, training, and state level agencies. In addition, the Summit has provided opportunities to network with other parents and regional providers. KYACA provided project funding for Parent Summits in FY 20 and FY 21. Due to the pandemic, the April 2020 Parent Summit in Barren River was cancelled and with continued concerns around the pandemic, another in person Parent Summit has not been possible. Currently, KYACA is exploring a virtual Parent Summit option. See Table 6 Below for map of previous Transition and Parent Summits dating back to 2015.

Table 6 –Parent & Transition Summit Map dating back to 2015



Autism Connect the Dots Dissemination Project

Under the direction KYACA Early Childhood Subcommittee, the Autism Connect the Dots Dissemination Project is a continuation of the original Autism Parent Support Project. The original pilot project was funded by KYACA and was created to assist families with children ages birth through 8 years old, who were newly diagnosed with autism, by offering six-week group sessions or hybrid day-long session co-led by a parent support group member and an Early Childhood Mental Health (ECMH) Specialist. This pilot project demonstrated the effectiveness of the content and skills attained in the group sessions with families and led to the development of the first training of the new curriculum to statewide family support leaders, state technical assistance and training professionals on March 4-5, 2020. Due to the pandemic, in person training has been postponed, recorded online modules were created, and access to these modules will be finalized by fall 2021

The curriculum for this pilot began as a social and emotional curriculum, called [*Connect the Dots*](#) that highlights four easy-to-remember steps (ensure supportive environments, encourage positive behaviors, emphasize positive discipline and embrace unique strengths) to address challenging behaviors often experienced with children ages 2 to 5 years. *Connect the Dots* is an approved training for early care and education training clock hours in KY and has been utilized in group and individual formats by behavioral health providers, DCBS prevention programs, Head Start staff, and other various early childhood partners throughout the state. To learn more about CTD, click [here](#)

Racial Equity Plan

In August 2020, KYACA began 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. Three goals of this plan below:

- The Executive Committee will work with Council & Subcommittee to integrate the racial equity commitments into the work and public facing efforts of the Council.
- Plan to increase and retain the representation of Black, Brown, Indigenous, Immigrant, and people of color on the Council, subcommittees, and volunteers.
- Goals and objectives aligned with Racial Equity Commitments across the subcommittees.

Tangible outcomes include:

- Adding Racial Equity Update/Discussion as a regular agenda item of Council to create regular and effective communication is a critical component of any initiative.
- 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 while we work toward our goals

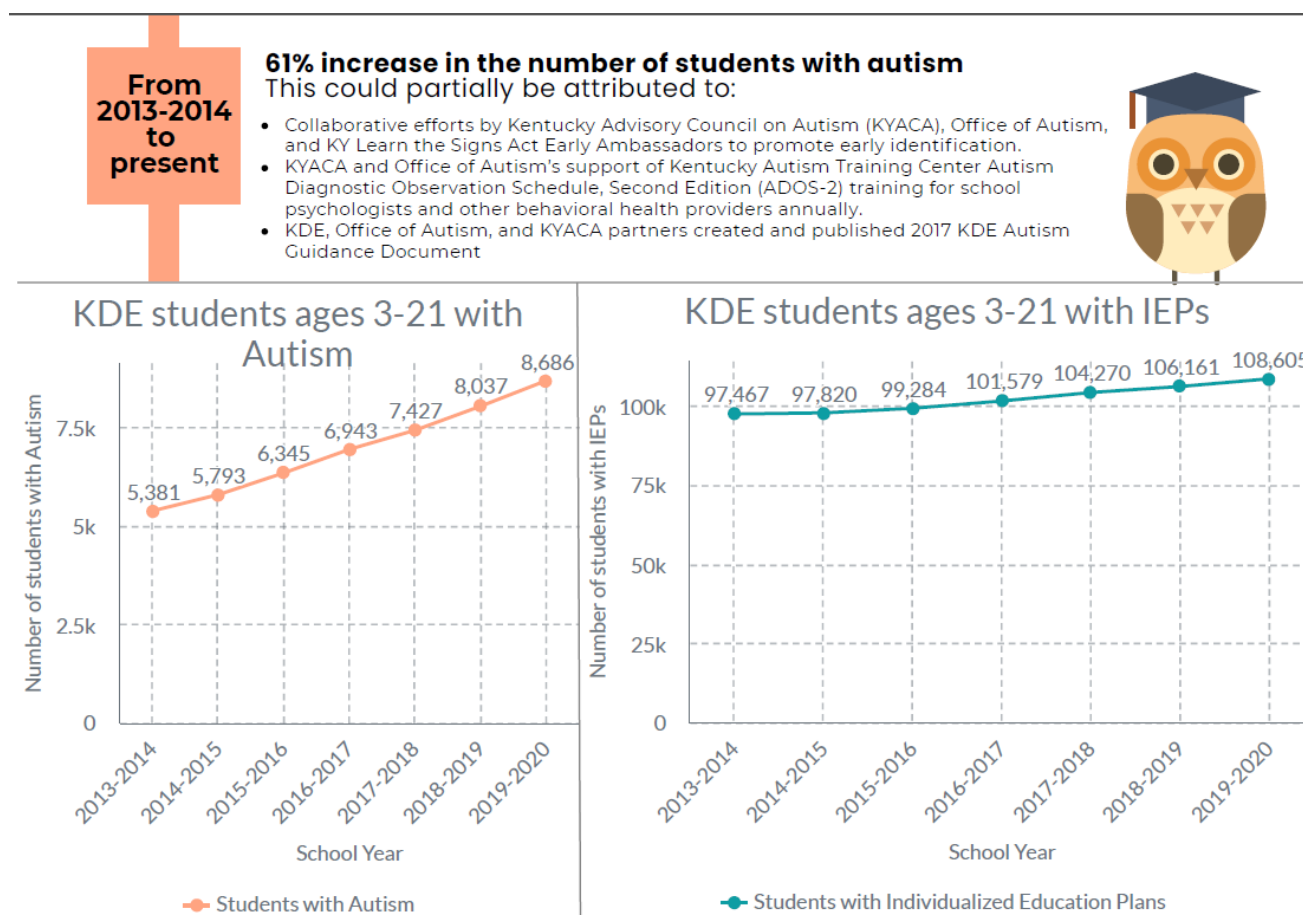
Autism Prevalence Infographic

Through collaboration and research, the KYACA created the [October 2020 Report: Kentucky Autism Prevalence Infographic](#). The purpose of this infographic is to promote awareness about national autism prevalence rates and to apply these national rates to the KY population, highlighting an increase in current autism rates. The national estimated rate for Autism Spectrum Disorder (ASD) is about 1 in 54 or 1.85 percent of a national sample of 8-year-olds. This prevalence is higher than that of the previous report in 2018, which found an ASD prevalence of 1.7 percent, or 1 in 59. Of course, these are estimated prevalence rates, and the rates of actual identification of children and adults are lower, and reflect a need to redouble our efforts to ensure that all individuals with ASD have the opportunity for accurate screening and diagnosis.

As part of this infographic, there are two line graphs titled “KDE Students ages 3-21 with Autism” and “KDE students ages 3-21 with IEPs”. Both graphs include data from the Kentucky Department of Education (KDE) Child Count Data from 2013-2014 through 2019-2020 School Year (SY). (See Table 7 below)

- These two charts were placed next to each other to show that while there has been an overall upward trend or increase in IEP student population over the last few years, the increase is not as pronounced as it is for those diagnosed with autism.
- Also, the number of students ages 3-21 with autism only captures a portion of the students with the medical diagnosis of autism in the schools.
- Students with a medical diagnosis of autism are also captured as IEP students in additional IEP categories like developmental delay, other health impaired, mild mental disability, functional mental disability, and emotional behavior disability.
- In addition, there are some students with autism not served through an IEP, but who are served under a 504 plan, and there are a few students served by the school system that do not have either a 504 or IEP.

Table 7 –Autism Prevalence Infographic second page- students with autism



For further narrative about the infographic, click [here](#)

KYACA PARTNERSHIPS

This section of the report describes KYACA partner agencies' collaborative efforts to support 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.

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

- **Community Work Transition Program** - The [Community Work Transition Program](#) is designed to provide a positive beginning in the world of work for students in special education during their last two years of high school. It is a cooperative effort between participating local school districts, the Kentucky Department of Education, the Kentucky Department of Vocational Rehabilitation, the Kentucky Department for the Blind, and HDI.

- **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. 9 of this report for detail of [ISAW](#).
- **KentuckyWorks** - [KentuckyWorks](#) aims to enhance employment opportunities for youth and young adults with intellectual and developmental disabilities throughout Kentucky. The KentuckyWorks State Team addresses barriers to employment for transition-age youth with significant disabilities. The work group is comprised of representatives from the KY Office of Vocational Rehabilitation (OVR), KY Department of Education (KDE), Human Development Institute, KY Division of Developmental and Intellectual Disabilities (DDID), KY Protection & Advocacy, Commonwealth Council on Developmental Disabilities, KY Office on Autism, KY Autism Training Center, Governor's Office on Early Childhood, KY Deaf-Blind Project and Department for Aging and Independent Living, as well as family members and self-advocates.
- **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.
- **Health and Wellness Initiative** - The [health and wellness initiative](#) at the Human Development Institute raises awareness of health disparities, while helping people with disabilities and their support networks take charge of their health. We provide resources via lessons, videos, activities, and tips on running effective health promotion programming for people with varying abilities, as well as updates on current statewide health initiatives and ways to get involved. Under this Initiative is [Project CHEER](#), which addresses the health disparities experienced by individuals with cognitive and mobility limitations through education, empowerment, and accessibility.
- **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 Employment First** is administered at HDI. [Employment First](#) is the philosophy that everyone, including people with significant disabilities, can work in integrated employment. In Kentucky, competitive and integrated employment in the community is the first and primary option for persons with disabilities of working age who have communicated a desire to become employed. Kentucky became an Employment First state on May 15, 2018.
- **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 including autism spectrum disorders (ASDs). 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 developmental disabilities, including ASD.
- **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 child care quality through training and technical assistance to child care providers, and connecting the community to resources that support quality child care.
- **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. [UK HDI](#) 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. Administration on Intellectual and Developmental Disabilities, 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 and Behavioral Pediatrics division (former Weisskopf Center)* and *Norton Children’s Division of Pediatric Behavioral and Mental Health (former Bingham Clinic)*. As the incidence of autism continues to increase, the NCAC has responded to meet the ever-growing need for evaluation, diagnosis, and treatment for the disorder. 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 and Behavioral Pediatrics division (former Weisskopf Center)

Norton Children’s Autism Center (NCAC) diagnostic services are concentrated at both at the NCAC and [Norton Children’s Developmental and Behavioral Pediatrics](#) (NCDBP) Center. The diagnosis of ASD is best

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 (Filipek et al., 2000; Filipek et al., 1999; Ozonoff et al., 2005; Stone & Ousley, 1996). Specific practice parameters for the diagnostic assessment of ASD have been published by the American Academy of Neurology (AAN) (Filipek et al., 2000), the American Academy of Child and Adolescent Psychiatry (AACAP) (Volkmar et al., 2014), the American Academy of Pediatrics (AAP) (Johnson, Myers, & CCD, 2007), the American Occupational Therapy Association (Tomchek & Koenig, 2016). 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 2020-2021, there were 4000+ diagnostic service encounters at the NCDBP Louisville location in support of 1,000+ unique patients.

First Steps Promoting Early Identification

The [Norton Children's Developmental and Behavioral Pediatrics](#) (NCDBP) Center continues key partnerships with CHFS-DPH targeting early identification. First Steps, Kentucky's Early Intervention System 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 First Steps providers on use of and interpretation of key findings when using early screening and diagnostic measures. Activities also supported the rapid shift to telehealth during the COVID-19 pandemic to ensure access to diagnostic evaluations. Follow-up intensive level diagnostic evaluations are performed at [Norton Children's Developmental and Behavioral Pediatrics](#) (NCDBP) Center. This collaboration has led to early identification evaluations for ASD for 78 children under age three in FY20 and 110 children under age three in FY21.

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 2020-2021, there were 9,000+ service encounters in the support of 3,700+ unique patients. The medical consultation practice including pediatric neurology, pediatric psychiatry, and developmental behavioral pediatrics had 4,000+ service encounters, which supported 2,000+ individual patients and their families.

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

The 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, and the Kentucky Autism Training Center. The main partnership activities of KAITTR focus on four (4) regional autism clinics in collaboration with the Office for Children with Special Health Care Needs (OCSHCN). To date, over 1,000 children, adolescents, and their families have received diagnostic services, medical consultation, and/or educational consultation services through these regional autism clinics in Somerset, Bowling Green, Lexington, 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 ASD and other developmental disabilities and their families. The clinics provide autism diagnostic assessments and consultation from 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 500 children with a

confirmed autism diagnosis by a neurologist, psychiatrist, and developmental pediatrician with specialized training in ASD. 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 facilitated by a single OCSHCN care coordinator. The KAITTR clinics are funded by the OCSHCN.

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 alongside the University of Louisville Autism Center. The program 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 persons affected by autism 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 those affected by ASD.

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 offers family assistance, community-based services related to supports and training, classroom consultation, school-based team consultations and programs in special education. KATC staff provide workshops and training seminars on topics of specific interest to families and professionals.

Kentucky Department of Education (KDE)

The [Kentucky Department of Education](#) (KDE), the [Kentucky Advisory Council on Autism](#) (KYACA), [Kentucky Autism Training Center](#) (KATC), the [Kentucky Special Education Cooperatives](#), and school districts have been receiving training on how to educate students with Autism Spectrum Disorder (ASD). Some schools have become training/observation sites for other districts to send new and master teachers for learning opportunities. Special education cooperatives assisted districts with setting up these rooms per the guidelines set by KATC. Additionally, special education cooperatives support teachers as they implement Individual Education Plans (IEPs) for students with ASD.

KDE, KATC, and KYACA have collaborated to develop statewide trainings for preschool teachers, assistants, and parents to further knowledge and understanding of autism and how to ensure these students are successful within preschool environments. These groups have been working to identify strengths and challenges in Kentucky's system of care toward the system-level coordination of the early screening, assessment, diagnosis, and intervention of ASD ages birth through age 5.

The KDE, KATC, and the KYACA have also collaborated over the past two years to complete the [Autism Guidance Document](#) for Kentucky school districts. In November 2017, this guidance document 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 3 and 21 to enable them to be successful in their environments. They have also worked to ensure information, training, and guidance are readily available to assist parents and districts with educating and transitioning all individuals with ASD. They have also worked together in training the cooperatives so they can train in their districts on the use of this document, as well as implement the training classrooms throughout the state. By working together, we are all able to meet the needs of parents and teachers/districts when educating and transitioning individuals throughout their life activities.

The KDE website houses resources specific to autism and related to autism including:

- [Autism Guidance Document](#)
- [Eligibility Determination Form—Autism](#)
- [Eligibility Record Review Document—Autism](#)
- [Parent and Family Resources](#)
- [Parent and Family Rights](#)
- [Parent and Family Toolbox](#)

Department for Public Health (DPH)

The Kentucky Part C Coordinator is an appointed member of the KYACA, representing First Steps and participates as a member of the early childhood subcommittee. Data on the number of toddlers identified with autism spectrum disorders is provided to the KYACA along with identification of barriers to child find (identification of potential First Steps children). First Steps procedures are modified when appropriate based on the information gained during council meetings. Tele-intervention was implemented as a service delivery option due to the COVID-19 state of emergency so that early intervention services could continue.

The Kentucky Early Intervention System, known as First Steps, 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 & Young Children (STAT). Collaboration with the University of Louisville Autism Center provided specialized training in screening, diagnosis, and intervention continued for early intervention service providers. These trainings further develop a foundation to build systemic and regional supports. DPH assisted with the development and piloting of the *Connect the Dots* for children with autism training adapted for parents and caregivers of children with the diagnosis of autism. This training program identifies social and emotional best practices that address challenging behaviors. The Connect the Dots is presented in six-week group sessions. The collaborators for this project includes the KYACA, the University of Louisville Autism Training Center, and DPH.

Department for Medicaid Services (DMS)

The Department for Medicaid Services 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, Medicaid added the billing codes specific for Applied Behavior Analysis on the Behavioral Health and Substance Use Disorder fee schedules. This will enable us to gather information on utilization of services provided by LBA's and LABA's.

The Division of Community Alternatives (DCA) paused a project to redesign the state's six 1915(c) HCBS waivers in early 2020. DMS is currently re-evaluating some of the recommendations included in the 1915(c) HCBS Waiver Assessment report to ensure that all recommendations are thoroughly vetted to eliminate or minimize unintended consequences. A special committee formed during the last legislative session is now reviewing previous waiver redesign efforts and developing recommendations to ensure quality and stability of waiver services in Kentucky. Of the state's six waivers, three may have an impact on individuals with intellectual and/or developmental disabilities. These waivers include the Home and Community Based waiver (HCB), the Supports for Community Living Waiver (SCL) and the Michelle P Waiver (MPW). Throughout this process DCA has considered all public input in the decision making process. DCA has worked to educate the populations served through increased stakeholder engagement. DCA has also made efforts to educate the Council on 1915(c) waiver background, overview, redesign, progress to date, and next steps. DCA has also worked to ensure that all stakeholders, including members of the Council, have the opportunity to make their voice heard and provided information and multiple avenues.

DCA continues to make operational updates designed to improve the waiver programs. In the fall of 2019, DCA shifted service authorization operations from a third-party entity to case managers or DMS staff, depending upon the service. DCA also operationalized the 1915(c) Waiver Help Desk as a central point of contact for waiver providers and participants.

In January 2020, DCA changed the way patient liability is calculated for waiver participants. The new calculations allow them to keep more of their income and reduce or eliminate patient liability for most waiver participants.

In late 2020, DCA shifted incident reporting from a paper process to an electronic process using the Medicaid Waiver Management Application (MWMA). This created a consistent incident reporting process, makes it quicker and easier for incident notifications to be made, and allows DMS, the Department for Aging and Independent Living, and the Department for Behavioral Health, Developmental and Intellectual Disabilities to better track and trend incidents and identify and mitigate potential risks to participants.

Finally, DCA is in the process of implementing electronic visit verification (EVV) as required by the 21st Century Cures Act. EVV captures six data elements about visits to deliver a participant's waiver services including the date of the service, state and end time of the service, location of the service, the name of the individual receiving the service and the name of the individual delivering the service. DCA contracted with Netsmart to provide the state-sponsored EVV solution. Providers can also choose to use their own, third-party EVV system. EVV use is required for certain services in five of Kentucky's six waivers, including HCB, MPW and SCL. About 25% of affected providers have begun using EVV to capture the six data elements and DCA expects all affected providers to adopt EVV by January 1, 2022.

Department for Behavioral Health Developmental and Intellectual Disabilities (DBHDID)

Kentucky Department for Behavioral Health, Developmental and Intellectual Disabilities' mission is to provide leadership, in partnership with others, to prevent disability, build resilience in individuals and their communities, and facilitate recovery for people whose lives have been affected by mental illness, intellectual disability or other developmental disability, or substance abuse.

Additionally, DBHDID is responsible for the administration of state and federally funded mental health and substance use treatment 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 intellectual or developmental disabilities, families, advocates, stakeholders and government agencies.

DBHDID Collaborations & Office of Autism

- The Office of Autism participates in weekly DBHDID Executive Team Staff meetings hosted by Wendy Morris, DBHDID Commissioner.
- The Office of Autism and DBHDID have been involved with the Department for Medicaid (DMS) process of redesigning the state's 1915(c) waivers. Three (3) of the waivers include individuals with autism including those with intellectual and/or developmental disabilities. These waivers include the Home and Community Based waiver (HCB), the Supports for Community Living Waiver (SCL) and the Michelle P Waiver (MPW).
- Office of Autism has been involved with DMS meetings with various Medicaid provider types in an effort to resolve billing issues to better serve the autism population.
- DBHDID has participated in quarterly meetings with DMS and the Medicaid Managed Care Organizations around service delivery issues including autism related services.

- Children’s Behavioral Health and Recovery Services Branch has staff serving on all three KYACA subcommittees
- DBHDID is actively involved in the Kentucky’s 988 Planning Coalition to implement a new 988 system in July 2022. Kentucky’s 988 Planning Coalition is assessing Kentucky’s current system capacity in order to meet the projected demand for 988-related services, creating a roadmap to fill any assessed system/community gaps, and solidifying a crisis system that delivers resources for those in need.
- The national 988 number will become the national three-digit dialing code for the National Suicide Prevention Lifeline, replacing the current phone number of 1-800-273-TALK. Once implemented, the 988 number will be America’s mental health safety net by providing emotional support for people in distress, reducing suicides and mental health crises, and providing a pathway to well-being for all.
- DBHDID works collaboratively on the Crisis Intervention Team (CIT) program, which is a community partnership of law enforcement, mental health and addiction professionals, individuals who live with mental illness and/or addiction disorders, their families and other advocates. This program is an innovative first-responder model of police-based crisis intervention training to help persons with mental disorders and/or addictions access medical treatment rather than place them in the criminal justice system due to illness related behaviors. It also seeks to promote officer safety and the safety of the individual in crisis. Crisis Intervention Teams (CIT) training includes a block of training on Developmental and Intellectual Disabilities and the total training is 40 hours.
- DBHDID assisted in the development of an additional CIT 2 training, which consists of 24 hours of total training. During the CIT 2 implementation process, CIT Advisory Boards were surveyed across the state for training topics and Autism was number one topic. CIT 2 Training was piloted in June 2021 in the Louisville area and included a block of training on Autism.
- DBHDID provides consultation to KDE on guidance documents related to student, family & staff mental health, and well-being as well as school practices and policies related to trauma, resilience, mental health, secondary trauma, etc. This consultation to KDE includes the intersection between trauma & equity & the necessity of addressing equity as part of being trauma-informed & resilience-oriented. Example collaborations include:
 - Project AWARE
 - School Climate Transformation Grant
 - Suicide Prevention/ MH Promotion programming (e.g. Sources of Strength)
 - Youth Mental Health First Aid
 - Training & implementation support & consultation for school-based CMHC Clinicians in trauma-informed & trauma-focused interventions (e.g. TARGET, TF-CBT, race-based trauma)
- The DBHDID collaborates with UK HDI and the Office of Autism on two specialized initiatives: (1) the Kentucky Work initiative, which is dedicated to employment opportunities for individuals with disabilities, and (2) the Kentucky Inclusive Health Collaborative, which focuses on the development of inclusive health programs, resources, and sustainable partnerships and networks across the state.

Office of Vocational Rehabilitation (OVR)

In Fiscal Year 2020, the Kentucky Office of Vocational Rehabilitation (OVR) reported serving 1,148 individuals with autism with the majority, (91.4% or 1,049 individuals) being transition age youth (Age 14-24). This number shows a decrease of individuals (557 or 33%) served in Fiscal Year 2018. For the previous report, expenditures totaled \$2,528,374 in Fiscal Year 2018. Expenditures in Fiscal Year 2019 were \$2,367,640 for a 10% decrease over the previous year. For Fiscal Year 2020, expenditures were \$2,388,330 for a slight increase in expenditures from 2019. The table below shares data for Fiscal Years 2019 and 2020, including the total amount spent on these consumers with autism r, along with the percentage breakdown of types of services. During the reported years, decrease in individuals served and amount spent showed some decreases due the growing trend to have more individuals served in Pre-Employment Transition Services before they become OVR consumers rather than Transitional Services once they become consumers of OVR. Also during the last

quarter reported, the COVID 19 pandemic changed in service school services to remote services and referrals in general declined.

Since 2014, OVR is mandated to spend 15% of its income to provide Pre-Employment Transition Services to potentially eligible high school students with a disability. These are students that are determined to have a disability by the schools but who have not applied, been accepted, or have a plan 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. Since they are not technically OVR consumers but potentially eligible students, reporting constraints do not allow OVR to show the exact number or percentage that are individuals with autism and funds for this are not included in the table below. OVR did provide Pre-Employment Services to 8,607 potentially eligible students in Fiscal Year 2019 and 14,870 potentially eligible students in Fiscal Year 2020.

OVR partners with the Office of Autism, Kentucky Autism Training Center, and the UK 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.

Table 8 - KY Office of Vocational Rehabilitation: Expenditures by Category for Individuals with ASD.

Category	\$ in 2019	% in 2019	\$ in 2020	% in 2020
Assessment	\$244,081	10%	\$243,865	10%
Diagnosis and Treatment	\$105,924	4%	\$126,505	5%
Training	\$246,727	10%	\$351,905	15%
Maintenance	\$9,116	< 1%	\$13,926	<1%
Transportation	\$3,338	<1%	\$3,939	<1%
Job Placement	\$790,957	33%	\$830,775	35%
Computers/Rehab. Technology	\$125,869	5%	\$102,823	4%
Pre-Employment Training Services for OVR consumers	\$508,838	21%	\$371,133	12%
Other	\$332,789	14%	\$343,460	16%
Total spent	\$2,367,640		\$2,388,330	

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. OCSHCN services related to Autism Spectrum Disorder (ASD) include developmental screening, diagnostic clinics, medical clinics, and care coordination. The ASD clinic team includes a combination of the following: neurologist, psychiatrist, psychologist, developmental pediatrician, speech pathologist, social worker, audiologist, nutritionist, and a nurse care coordinator. Because of these services, OCSHCN remains highly involved with the Office of Autism in the following ways:

- The Office of Autism shares a multitude of information about ASD programs and services across the Commonwealth. The availability of the information allows OCSHCN care coordinators to guide families and make referrals to appropriate services.
- OCSHCN's leadership and care coordinators are active participants in the Autism Diagnostic & Medical Follow-Up Collaborative Community of Practice. 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 Executive Director serves on the Kentucky Advisory Council on Autism (KYACA) and OCSHCN's Nurse Administrator based in Somerset participates in the School Aged Subcommittee of the KYACA.
- The Office of Autism participates in quarterly OCSHCN Autism Partnership meetings specific to OCSHCN ASD gap filling services. The Office of Autism is knowledgeable about OCSHCN programs and thus refers families/providers to OCSHCN as appropriate.
- 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.
- The Office of Autism assists in the promotion of OCSHCN's Extension in Community Healthcare Outcomes (ECHO) Autism Project.

Department for Community Based Services

As of July 9, 2021, there were 322 children currently in Department for Community Based Services (DCBS) custody with a diagnosis of autism spectrum disorder (ASD). Of these 322 children, 299 children were in out-of-home care with 12 in acute psychiatric hospitals, 106 children were in private child-caring residential treatment facilities (RTF), 133 were in private child placing agency foster homes and 13 in DCBS foster homes. In addition, 30 children were in other placements with 20 in parent/relative homes, 17 in placement with a current Support for Community Living (SCL) provider, 9 in Independent Living Programs, and 2 in a psychiatric residential treatment facility (PRTF).

Table 9 - 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	12
6 to 11 years	81
12 to 17 years	173
18 to 21 years	56

According to Medicaid and pharmacy claims, in the 12-month period ending Sept. 30, 2020, DCBS had served 928 (8.5%) children with autism spectrum disorder (ASD). Analyses of gender, race and ethnicity revealed 633

children were male (68.2%) and 593 (63.9%) were White, 43 (4.6%) were Black, 17 (1.8%) were Hispanic, and 292 (31.5%) were Other

This population is a complex group with multiple medical and emotional needs. ADHD (N=434, 46.8%), Anxiety Disorders (N=227, 24.5%) and PTSD (N=182, 19.6%) were frequent comorbid psychiatric diagnoses. Of this group, 579 (63.0%) were treated with psychotropic medications. The most common classes of medications used in this population were alpha-agonists (N=402, 70.3%) and antipsychotic medications (N=365, 63.0%).

Children with ASD may present special challenges to DCBS.

- Children with ASD in DCBS custody are more likely to have trouble with placement in the appropriate level of care and are at greater risk for out of state placement
- Children with ASD with a lack of access to evidence-based specialized treatments such as applied behavioral analysis are more likely to enter DCBS custody as dependents
- Children with ASD who transition into adulthood face challenges in finding independent living or supported housing placements
- Obtaining timely diagnostic testing and access to specialized services such as applied behavioral analysis with appropriately trained providers can often be an issue for children in DCBS custody with ASD.

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 (ASD) and Developmental and Intellectual Disabilities (DDID) 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.

Children with ASD, like all children in DCBS custody, are often treated with multiple psychotropic medications. DCBS is engaged in multiple activities to track and improve the quality of medication treatments delivered to children in their custody. These include medication consults led by the DCBS Medical Director to review complex cases and determine best practices. These calls commonly address the unique issues presented by children with ASD and/or intellectual disabilities.

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 ASD. This branch has ongoing consultation and case management between the Medical Director, Central Office, the Service Regional Clinical Associates, and the child's social worker in each region of the state.

Since Jan. 1, 2021, DCBS has been served by a single Managed Care Organization (MCO); Aetna SKY that features focused case management and quality activities to serve children with complex needs such as ASD. In addition, beginning in May 2021 DCBS hired regional Nurse Clinical Investigators formerly employed by the Office for Children with Special Health Care Needs (OCSHCN) 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, and

systemic work. P&A serves individuals of all ages, cross-disability, and is a client-directed agency where the individual with a disability or who is deaf or hard of hearing is the client. P&A takes case direction directly from the client.

The COVID pandemic had a significant impact on P&A's function and the needs of their clients. While P&A offices were closed, P&A was unable to maintain a presence in institutions or meet face-to-face with clients. P&A was able to use technology to continue to advocate for and serve clients. P&A advocates and attorneys successfully pivoted to a virtual monitoring format to protect the safety of clients—many of whom were particularly vulnerable to the virus. Vaccine availability has allowed P&A staff to return to in-person client visits and monitoring. P&A believes the creativity and flexibility developed during the pandemic will help P&A to broaden and improve services.

P&A advocates and attorneys provide individual representation to individuals with disabilities across the state on a wide array of issues. During the 2019-20 fiscal year, P&A provided services to 1,891 individuals through individual and systemic advocacy. Of that number, 312 (16%) were specifically identified as being on the autism spectrum or having a pervasive developmental disability. P&A assisted clients with autism on a wide variety of issues, including obtaining a free and appropriate education, park access, housing, employment, and transition services; providing information and referral and technical assistance; and obtaining appropriate healthcare services.

P&A also advocates—often with other state and local agencies—to address systemic issues. For example, P&A led a statewide collaborative with agencies like the Autism Self Advocacy Network to ensure the Crisis Standards of Care (a document that informs hospital decisions when resources are scarce) did not allow or encourage discriminatory care and treatment of the COVID virus. Similarly, P&A worked at both the state and federal level to ensure students with disabilities had access to a free and appropriate education during the pandemic while school buildings were closed. P&A attorneys also successfully advocated for regulatory changes to the Supports for Community Waiver, which allow applicants to appeal their placement on a waiting list for services.

P&A staff and advisory boards are constant in their dedication to advocating for the change necessary to secure the agency's vision of an integrated and inclusive society where everyone is afforded the opportunity to live self-determined lives and where differences are valued.

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) 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. The Arc believes that individuals with intellectual and developmental disabilities are contributing members of schools, work places, churches, synagogues, neighborhoods, and their communities. The Arc values services and supports that enhance the quality of life through interdependence, friendship, choice, and respect for individuals with intellectual and developmental disabilities.

During 2020, with the difficulties faced because of pandemic, activities were postponed throughout the year. In 2019, the activities and events below were accomplished and plans are in place to restart when and where possible. The Arc is concerned with the limited degree the issue of COVID-19 vaccination and autistic individuals' common reluctance or fear of injections has received within the government or the medical profession. The Arc hopes to aid in enlightening the public during the remainder of the year about this concern through awareness. 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.

In 2019, The Arc hosted three airport rehearsal events across the state called Wings for Autism®, which is one of The Arc's newest national initiatives. This program allows for individuals with autism spectrum disorders and other intellectual and developmental disabilities, as well as their families, to simulate the airport experience. This includes practice entering the airport, going through Transportation Security Administration (TSA) security, waiting in the gate area, and boarding the plane. The Arc partnered with FEAT of Louisville and The Autism Society of the Bluegrass to serve more individuals with autism at the Wings for Autism® events.

The Arc has created a Self-Empowerment Network, which serves individuals with disabilities including autism across the state. The advocates have been working on improving community access, housing opportunities, transportation, employment opportunities, and education. The Self-Empowerment group spoke at the annual conference, which reached individuals statewide on a variety of topics such as community leadership, creating vision boards to advocate for change, support system challenges, education, sexuality, dating and marriage. With regard to legislation, self-advocates submitted input for legislation on supported decision-making.

The Arc offers a statewide conference to bring a best practice to reach over 400 people through networking with a variety of exhibitors, speakers, professionals, participants, and self-advocates. In 2019, Arc had a national speaker from The Autism Society of America. Self-advocates were able to attend and promote their self-employment businesses.

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.

CCD is governed by and agrees with the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) of 2000 that states: "disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society." DD Councils are funded through the federal appropriations process. Specifically, they are allocated funding through the Administration on Intellectual and Developmental Disabilities (AIDD) under the US Department of Health and Human Services.

CCDD has one representative that is appointed to the KYACA. This representative has autism or 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 & 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 home-ownership, multi-family housing, co-housing with non-disabled peers, community land trusts, and tenancy.

Kentucky Works

[KentuckyWorks](#) is a collaborative effort between the UK HDI, Office of Vocational Rehabilitation, Department of Education, Division of Developmental and Intellectual Disabilities, Protection & Advocacy, Commonwealth Council on Developmental Disabilities, Office of Autism, Governor's Office on Early Childhood, Department of Aging and Independent Living, Deaf-Blind Project and the Kentucky Autism Training Center. It focuses on employment for people with developmental disabilities and serves to find training and resources that everyone on the employment team can use to help students with disabilities get jobs.

Kentucky Telehealth Law Update

In 2021, the state Legislature passed updated telehealth laws that increase the availability of telemedicine to persons across the Commonwealth. Kentucky Medicaid and the Kentucky Department of Insurance have proposed administrative regulations, which support broad use of and provider reimbursement of telemedicine.

The legislature took note of providers and patients' statements on the utility and effectiveness of telehealth. Some individuals who are challenged by physically accessing a healthcare provider's office may more easily access care via telehealth (audio or video communication with the provider). For persons with autism, telehealth can allow them to control or reduce inappropriate or distracting stimulations such as lighting, external noise, presence of other individuals, etc., and focus on the issue at hand. Telemedicine can also reduce anxiety in persons who can control that by choosing the method of contact with the healthcare 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.

Use of telehealth requires patient consent, either written or verbal. KRS 311.5975

Any provider can render care via telehealth if their licensure board permits it. KRS 304.17A.138. Telehealth services are reimbursable by Medicaid where the telehealth providers shall be: (a) Currently enrolled as a Medicaid provider in accordance with 907 KAR 1:672; (b) Currently participating as a Medicaid provider in accordance with 907 KAR 1:671; (c) Operating within the scope of the provider's professional licensure; and (d) Operating within the provider's scope of practice. The same applies for commercial insurance. KRS 304.17A.005.

Healthcare providers delivering care via telehealth shall be held to the same standards as when they are delivering in-person care and operating within the scope of the provider's professional licensure and scope of practice.

The Kentucky Division of Telehealth Services, Donna Veno, Director, and the Kentucky Telehealth Steering Board are available to address any questions patients or providers have about use or insurance coverage of telehealth. The [state Telehealth Website](#) contains a variety of resources about use of telehealth in the Commonwealth, including "FAQ's" and training on using telehealth for both patients and providers.

Telehealth is a wonderful resource available to persons with autism and any provider engaging in treatment or therapy (including dental or vision, occupational or speech therapy, or even basic health and wellness care).

CONCLUSION

The Advisory Council on Autism will continue to utilize legislation as a road map to the advancement of services and supports to families of the Commonwealth. The KYACA and subcommittees will seek opportunities for both legislative and policy changes that further the completion of the recommendations, statutory goals, and aligned strategic plan.