2020 PURSUING QUALITY LIVES

Supporting Ohioans with Autism Across Agencies, Across the State, Across the Lifespan

Ohio | Interagency Work Group on Autism

TABLE OF CONTENTS

Please note: The terms "person with autism," "person with ASD," "autistic person," and "person on the autism spectrum" are used interchangeably throughout this document. Some members of the autism community prefer one term, while others prefer another. The IWGA respects the different opinions within the community on the use of this language and does not intend to endorse any particular preference. In addition, the terms "autism" and "autism spectrum disorder (ASD)" are used interchangeably throughout this document unless otherwise noted.

BACKGROUND

Nearly 20 years ago, the Ohio Autism Taskforce (OAT) issued 43 recommendations which constituted Ohio's first autism action plan. The OAT recommendations laid the foundation for Ohio's on-going autism efforts and infrastructure, including the creation of the Interagency Work Group on Autism (IWGA), the Ohio Center for Autism and Low Incidence, now known as OCALI, and its advisory board.

The OAT recommendations have been updated and revised over the years, initially in Quality Lives (2012) and then Pursuing Quality Lives (2018). The guiding principles remain the same:

- **Get a good start.** Identification and diagnosis can happen at any age and should occur at the first suspected signs.
- **Obtain needed services.** Individuals with ASD should have access to high-quality services.
- **Develop skills to succeed.** Life skills develop and change as an individual grows. Skill development is a continuous need throughout an individual's life.
- **Strengthen support along the way.** Family is the most important, consistent, and instrumental influence in a child's life. A strong base of support is important.
- **Help others understand.** It is imperative that professionals and community members recognize and understand the characteristics of ASD to serve, support, and empower individuals and their families.
- **Live well.** Knowing how to network and navigate available community resources is fundamental to developing and sustaining effective supports for a successful future.
- **Sustain the future.** Thoughtful planning and coordination is necessary to uphold broad, but connected, service systems that are responsive to individuals with ASD and their families.

For 2020, Pursuing Quality Lives has been updated to reflect input from and alignment with:

- National data
- Family Surveys
- Transition Survey (youth/young adults with autism)
- IWGA members
- OCALI Center Directors
- OCALI Advisory Board
- DeWine administration and IWGA agency strategic plans and priorities

IWGA Membership

MEMBERS INCLUDE:

- Ohio Department of Developmental Disabilities (DODD) - Lead Agency
- OCALI - Convener
- Ohio Department of Education (ODE)
- Ohio Department of Health (ODH)
- Ohio Department of Job and Family Services (ODJFS)
- Ohio Department of Medicaid (ODM)
- Ohio Department of Mental Health and Addiction Services (OMHAS)
- Opportunities for Ohioans with Disabilities (OOD)

Foundational to this work is the voice of individuals and families. The IWGA seeks input and utilizes OCALI's advisory board and annual surveys as the primary means for parents, individuals, advocacy groups, and other stakeholders to contribute to the state's autism policy development and implementation.

Collective Impact

Rather than state agencies and supporting organizations working in isolation, Ohio has adopted a collective impact approach in responding to autism. Collective impact initiatives allow diverse stakeholders to work together on complex issues and achieve greater results than they would alone. The approach includes five elements:

1. **Common agenda.** The Interagency Work Group on Autism developed, adopted, and endorsed Pursuing Quality Lives (PQL) to serve as its common agenda. The IWGA utilizes PQL to organize IWGA meetings and activities, gather data and research, and report on targeted priorities. The member-agencies of the IWGA built PQL on the foundation of the original "Quality Lives" recommendations, updating them for 2018 (and beyond), and affirming the vision and commitment to, "work with quality and integrity - to support the best trajectory of life outcomes for Ohioans with ASD and their families, infancy through adulthood."
2. **Shared measurement systems.** In 2018, the IWGA began using the following framework for a shared measurement system relative to PQL (adapted from the State Health Improvement Plan).
    a. Metric Selection Criteria
        i. State-level: Statewide data is available
        ii. U.S.: U.S. data is available for comparison
        iii. Reputable: Metric is nationally recognized (not home-grown)
        iv. Trend: Trend data is available for at least two years (or will be)
        v. Source integrity and data quality: Data are complete and accurate; response rates and sample sizes are adequate (if survey data)
    b. Preference Given to Metrics With:
        i. Sub-state geography: Data are available at the regional/county level
        ii. Alignment: Metric aligns across two or more sources (Maternal and Child Health National Outcome Measures, National Autism Indicators Report, State agency metrics, etc.)
        iii. Benchmarks: Benchmark values have been established for the metric by a reputable state or national organization or agency (e.g., Early Intervention Annual Performance Measures, Healthy People 2020)
        iv. Face value: Metric is easily understood by the public and policymakers
    c. Metric duplication: Avoid metric duplication. Remove similar metrics, keeping metrics that best meet the above criteria.

    The IWGA has effectively used this framework to look at data relative to the targeted priorities in PQL.

3. **Mutually reinforcing activities.** Monthly, IWGA members are given the opportunity to report to one another on their member-agencies' activities, priorities, and efforts related to IWGA and PQL. This provides accountability and engagement of the members, and opportunities for resources sharing and follow up.

    In addition to this "roundtable" at IWGA, the member-agencies are also working collectively on and holding one another accountable for, implementing the targeted priorities in PQL.
4. **Continuous communication.** While the member-agencies represented on IWGA have remained the same, agency-representatives have changed. To minimize the impact this has on continuous communication, and maximize the IWGA's time

together, the IWGA adopted standardized meeting protocols, distributes materials in advance of meetings, hosts “ad hoc” meetings to address critical issues, and utilizes communication “calendars” and templates for social media and other informational campaigns.

5. **Backbone support organization.** OCALI acts as the backbone support organization for the IWGA, setting the agenda (based on the priorities established by the group), gathering and analyzing data, organizing speakers/presentations, distributing resources, following up on action items, and implementing many of the IWGA’s initiatives. OCALI ensures agendas are distributed, members have materials in advance of meetings, makes all room arrangements, maintains the IWGA website, prepares/distributes copies of IWGA documents (i.e., Pursuing Quality Lives), represents the IWGA at conferences, on workgroups, and as requested in meetings with legislators and other policymakers, often acting in an advisory role for member-agencies.

   Additionally, OCALI ensures member-agencies are aware of opportunities, including conferences, training, and webinars to build the capacity of the individual members.

Race, Ethnicity, and Autism

A growing body of research demonstrates people of color and their families experience significant disparities when it comes to autism. Data and action items related to these disparities are included throughout the report. Some particular areas of disparity include:

- **Service provision:** Treatment disparities exist in timely access to care, referral frequency, number of service hours, and proportion of unmet service needs. Children from racial and ethnic minority groups and low-income families have less access to acute care, specialized services, educational services, and community services compared with higher-income and white families.
- **Young adults with autism:** Black or African American teens had the highest rates of medication for emotion, concentration or behavior; the highest rates of unmet health care needs; more difficulty than their peers in communication, self-care, and adaptive behaviors, and independently getting places outside the home; and were more likely to receive SSI benefits than teens with ASD of other races or ethnicities.
- **Material hardship:** Parents of black and Hispanic children with ASD experience greater difficulty paying for basics like utilities or housing, affording adequate food, and paying for medical bills.

GET A GOOD START

Identification and diagnosis can happen at any age and should occur at the first suspected signs.

What We Know

The Centers for Disease Control now estimates 1 in 54 children have autism. Based on this prevalence rate, it is likely more than 10,000 Ohio children between the ages of 5 and 8 have autism, and boys are more likely to be diagnosed than girls.[1] Research also demonstrates early interventions for autism are more likely to have major long-term positive effects on the core symptoms of autism and later life skills.

Autism can be reliably diagnosed as early as age 2, yet most children are being diagnosed around age 4 or later. While pediatricians are increasingly screening for autism, nearly 40% are not, and when screening results in a "flag" or "concern," many pediatricians make no referral for additional testing or services. Families who do raise concerns are often told to "wait and see." While there is a gap from initial concern to diagnosis for all families, the gap widens for racial and ethnic minority groups.[i]

While some children are first diagnosed with autism by a doctor or other medical professional, others may never be diagnosed, but rather are identified as a student with autism through their schools. Schools do not need and cannot require a diagnosis to determine eligibility for special education services – however, many do. Nationally, approximately 13-15 percent of children under the age of 6 have special needs that often warrant special education services, however, fewer than 6% receive them.[ii]

Ohio Strengths

- Autism Diagnosis Education Project (ADEP) has modeled an approach that significantly reduces wait times and age of diagnosis.[iii]
- Ohio family survey revealed over 80% of families were connected or got connected with services or resources at the time of diagnosis; 65% receive/received Early Intervention; over 90% receive/received services through their school.
- Ohio Early Intervention is investing in targeted outreach to primary care physicians and early care workers specific to making referrals and increasing knowledge of recommended early identification practices.
- OCALI's "ED ID" series has trained over one-third (225) of Ohio's school districts in the educational identification of autism.

---

[1] Methodology: CDC prevalence rate applied to Ohio's live birth rate in the years 2012-2015. The number of live births closely corresponds to school enrollment rates.

Targeted Priorities

The following have been identified as priorities for the IWGA over the next two years:

1. Culturally competent outreach to **families.**
2. Capacity-building specific to screening and diagnosis in the **medical community.**
3. Capacity-building specific to screening and identification in the **educational community.**

OBTAIN NEEDED SERVICES

Individuals with ASD should have access to high-quality services.

What We Know

Once identification and diagnosis have been made, people with ASD and their families benefit from a variety of services and supports – however, many of those are hard to come by. In early childhood, parents of children with disabilities experience difficulty finding quality childcare and are significantly more likely to experience job disruptions than parents of children without disabilities – leading to financial strains, health challenges, and increased stress.[iv]

Children from racial or ethnic minority groups and low-income families experience disparities in timely access to care, referral frequency, number of service hours, and proportion of unmet service needs. These children have less access to acute care, specialized services, educational services, and community services compared with higher-income and white families.[v]

Contributing to wait times, delays, and service scarcities are workforce issues – the top-ranked shortages affecting children's hospitals' ability to deliver care are the specialties needed by children with an autism spectrum disorder.[vi]

A growing body of research has shown people with autism experience high levels of co-occurring physical and mental health conditions. The most common conditions include epilepsy, gastrointestinal and sleep disorders. People with autism are also significantly more likely to experience attention deficit hyperactivity disorder, depression, anxiety, and bipolar disorder.[vii]

Children and youth with ASD are more likely to visit an emergency department for psychiatric problems,[viii] have more outpatient and inpatient hospital visits, primary care and psychiatric visits, health care claims, and higher health care costs than youth with other disabilities.[ix]

Of particular concern for youth with ASD is suicide. Between 2013-2017, the risk for suicide was higher for individuals with ASD than individuals without ASD, and adolescent males with ASD are two times more likely to be at risk for suicide than adolescent males without ASD.[x]

Ohio Strengths

- Ohio's Early Childhood Mental Health initiative supports evidence-based training, technical assistance, and consultation for parents and caregivers across the state. The initiative includes an Infant Mental Health Credential for Ohio's early childhood system aimed at promoting infant vitality and positive health and wellness outcomes.
- The Ohio Department of Developmental Disabilities has worked with OCALI's Center for the Young Child to develop tools, resources, training, and materials to support early childhood professionals.
- Through OCALI, the Ohio Department of Education offers a "Preschool Autism Training Series" – building the capacity of preschool personnel and programs to understand the needs of children with autism and design individualized interventions that are evidence-based and systematically implemented throughout the day.
- Ohio has invested in capacity-building to support "multi-system youth," including youth with autism. These efforts have focused on training for families and direct support professionals, technical assistance and consultation to the provider community through Project ECHO, and flexible funds to provide community-based services.
- The Ohio Department of Mental Health and Addiction Services and the Ohio Department of Developmental Disabilities jointly established a Mental Illness/Developmental Disabilities Coordinating Center of Excellence (MI/DD CCOE) to provide technical assistance and build the capacity of local teams across the state as well as provide second opinion assessments and develop greater collaboration across systems.
- The MI/DD CCOE also operates Ohio's Telepsychiatry Project, serving children and adults with co-occurring developmental or intellectual disabilities and mental or behavioral health conditions throughout the state.

Targeted Priorities

The following have been identified as priorities:

1. Access to **quality early care and education.**
2. Areas of **disparity or disproportionality,** including rural areas of the state and/or "service deserts."
3. **Co-occurring conditions,** specifically mental health and autism.

DEVELOP SKILLS TO SUCCEED

Life skills develop and change as an individual grows. Skill development is a continuous need throughout an individual's life.

What We Know

According to the US Department of Education, the percent of students with autism has more than doubled in the past 10 years.[xi] School systems have been challenged to keep up with this increased need for more, and more well-trained personnel.[xii] Less than half of special education degree programs offer coursework or competencies specific to autism, general education teachers receive little to no training in autism, and school districts cannot find teachers or related service providers to work with autistic students.[xiii]

While inclusion in the general education classroom is the ideal place for many students with autism to develop skills, in the 2018-19 school year, students identified with autism spent significantly less time inside the general education classroom than all other students with disabilities.[xiv]

Young adults with autism have the lowest rates of independent living—the majority of those who live independently are white (27%) compared to black and Hispanic young adults (0%).[xv] Many young adults with autism cannot get to places outside the home very well or are not allowed to do so at all—this is especially true for autistic teens who are black.[xvi]

Self-advocacy and daily living skills (i.e., personal hygiene, meal preparation, money management, etc.) are essential to sustaining employment or achieving academic success; however, less than 25% of adults with ASD have ever participated in self-advocacy (group, meeting, event).[xvii] An early opportunity for self-advocacy, and a predictor of post-school success, is participation in Individualized Education Program (IEP) meetings, yet many teens with autism do not participate – those most likely to participate come from higher-income households. [xviii]

Mainstream, assistive, and other technologies have also been shown to increase independence, life skills, and quality of life and reduce the need for formal supports.[xix] However, people with disabilities and their support systems are not adopting these technologies at the same rate as people without disabilities, and do not have the same access to broadband or devices.[xx]

Ohio Strengths

- Ohio's Employment First Taskforce partnered with Project STIR™ (Steps Toward Independence and Responsibility) to offer training and provide tools for job seekers to advocate, connect with other advocates, and gain leadership experiences that can lead to community employment. The Taskforce also created on-line modules for job seekers with disabilities, including one focused on self-advocacy.
- OOD partners with the Ohio Statewide Independent Living Council on a series of regional Youth Leadership Forums (YLF), a five-day career leadership training program for 11th and 12th-grade high school students with disabilities.
- On behalf of state partners, OCALI develops and maintains on-line training in evidence-based practices for families, caregivers, and professionals, including the Autism Certification Center (ACC), Autism Internet Modules, and other resources and materials which have been accessed by over 60,000 Ohioans.
- The Ohio Department of Developmental Disabilities leads the nation in launching a "Technology First" effort. The goal of "Technology First" is to ensure technology is considered as part of all service and support plans for people with disabilities and aims to help people learn more about how to use technology to improve their quality of life, experience more independence and personal freedom.
- DODD also partnered with The Ohio State University Nisonger Center to establish "The Technology Project," which aims to investigate technology solutions, promote independence for people with developmental disabilities and their families, create a vision for how technology may be improved and expanded upon, and identify technological advances that might benefit people with developmental disabilities by increasing their independence.
- To increase awareness and access to resources found in assistive technology libraries Ohio's Developmental Disabilities Council worked with OCALI to create a "Guide to Assistive Technology Lending Libraries in Ohio."

Targeted Priorities

The following have been identified as priorities:

1. People with autism increasing **self-advocacy, self-determination, and "soft" skills**.
2. Educators receiving support and training in **personalized learning** and **differentiated instruction** that is **culturally relevant.**
3. Ohioans building knowledge of and capacity for **using technology to increase independence and quality of life.**

STRENGTHEN SUPPORT ALONG THE WAY

Family is the most important, consistent, and instrumental influence in a child's life. A strong base of support is important.

What We Know

Families of children with ASD are more likely to experience particular hardships. For example, they are more likely to report financial problems and need additional resources for their child's medical care than caregivers of children with other developmental disabilities and mental health conditions.[xxi]

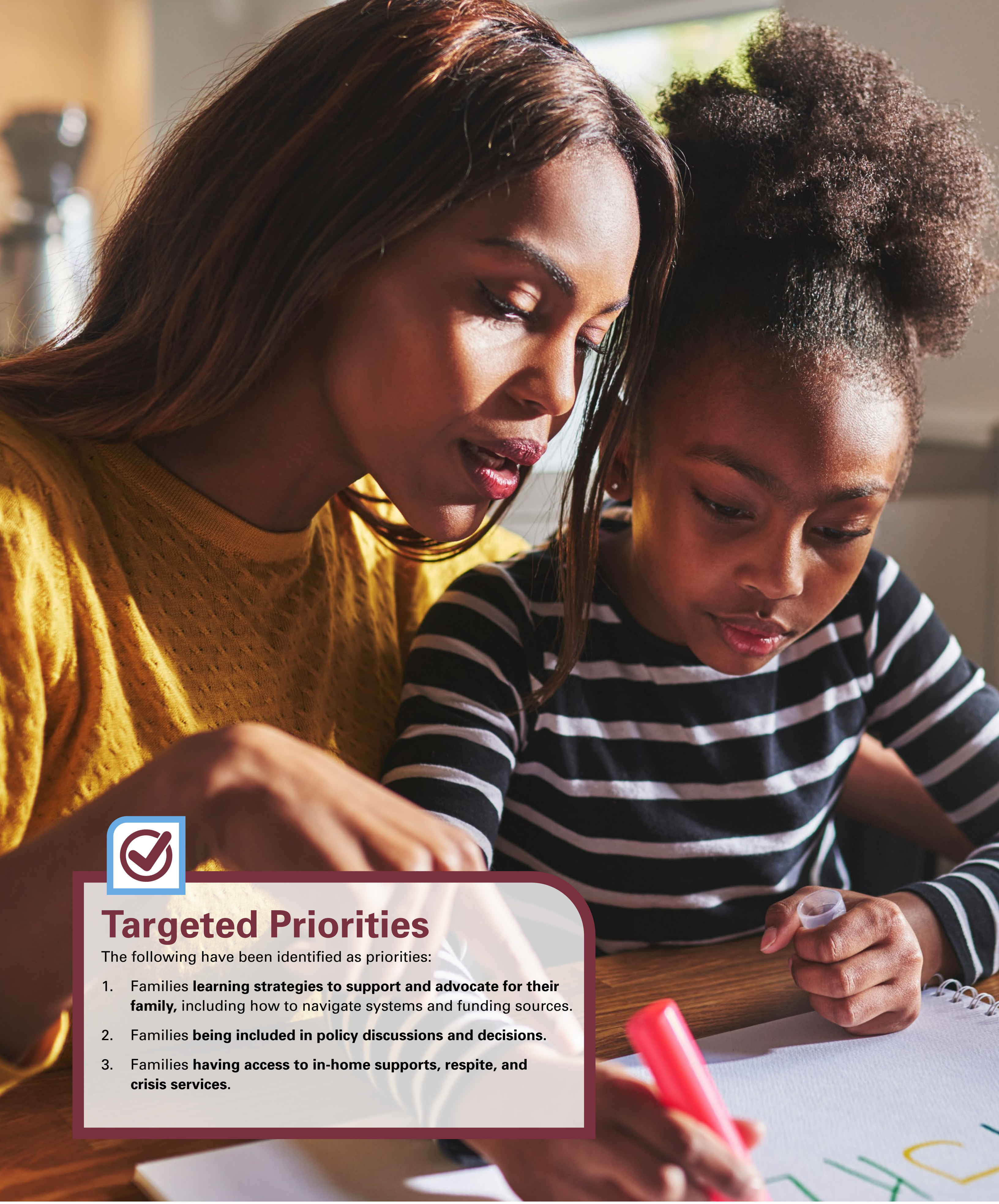
Almost 1/3 of parents of children with ASD have had to reduce their work hours to care for their child - compared to 12% of parents of children with special health care needs (SHCN) and 2% of parents of children with no SHCN.[xxii] Mothers of children with ASD are less likely to work outside the home. When they do, they work fewer hours and earn 56% less than mothers of children with no health limitations and 35% less than mothers of children with other special health care needs.[xxiii]

Additionally, parents of children with ASD experienced overall material hardship (paying bills, having enough food, etc.) much more often than parents of children with other SHCN and parents of children with no SHCN. Parents who were black or Hispanic experienced the highest levels of material hardship.[xxiv]

Nearly 60% of children with autism are living in "low-income households" (below 200% of federal poverty level) and participating in one or more public assistance programs.[xxv] Children with ASD from low-income households were more likely to be non-White, to live in a household headed by a single mother, and to have at least one sibling with an SHCN.[xxvi]

Ohio Strengths

- DODD has supported several initiatives to strengthen families, including grants to family lead organizations, developing family networks throughout the state, and offering training in "Growing Family Resilience" to. In addition, they host a monthly Family Advisory Council (FAC) headed by a core group of families and has expanded family membership in working groups.
- Ohio was one of 5 states chosen to participate in a national family leadership project. ODH and Ohio's F2F formed a Collaborative Action Team to encourage parents from underserved populations in Ohio to join advisory groups on local, regional, and statewide levels. The project also offers implicit bias training and specifically recruits families from racial and ethnic minorities.
- OMHAS and other state partners help make Parent Advocacy Connection and parent peer support available through NAMI. These efforts connect families with other families who have lived experience and can provide support and information.
- ODE funds parent mentors throughout the state of Ohio. Parent mentors are the parent of a child with a disability and are employed by a local education agency or education service center. Parent mentors provide families support, information, training, and connection to community resources.
- Ohio was chosen to participate in the National Community of Practice for Supporting Families. The Community of Practice utilizes Charting the LifeCourse, a framework designed to support families to maximize their capacity, strengths, and unique abilities to best nurture, love, and support their family members to achieve goals. DODD supports Charting the LifeCourse Ambassadors throughout the state who introduce this framework to families, schools, providers of service, community businesses, and county boards of developmental disabilities.



Targeted Priorities

The following have been identified as priorities:

1. Families **learning strategies to support and advocate for their family,** including how to navigate systems and funding sources.
2. Families **being included in policy discussions and decisions.**
3. Families **having access to in-home supports, respite, and crisis services.**

HELP OTHERS UNDERSTAND

It is imperative that professionals and community members recognize and understand the characteristics of ASD to serve, support, and empower individuals and their families.

What We Know

There is a significant lack of understanding and acceptance when it comes to autism. Beginning in childhood, students with ASD are bullied by peers at a rate 3-4 times that of non-disabled peers.[xxvii] In fact, 1 out of 2 students with autism are victims of bullying. Bullying is more likely to occur outside of special education settings, leading researchers to believe autistic students in the general education classroom or school environment are being rejected or victimized simply for being different.[xxviii]

Nearly one in three young adults with autism has had no community participation in the past year—no volunteer or community service, no lessons or classes, no other community activities outside of school.[xxix] Additionally, adults on the autism spectrum report that a lack of public understanding contributed to their experiences of social isolation and anxiety.[xxx]

Attitudinal barriers also impact autistic adults' access to employment. Paid, community-based employment was the least common outcome for adults with ASD.[xxxi] While skill development and education are key to addressing the "supply" side of the equation, research has shown that the belief systems of employers and hiring managers have significant negative impacts, and is often the primary barrier in hiring managers selecting an autistic candidate.[xxxii]

In addition, medical providers report a lack of comfort in providing care to individuals with autism—who experience comparatively poor health. On average, the health of children on the autism spectrum is worse than the health of children with SHCN and children with No SHCN.[xxxiii] This is also true for adults on the spectrum, who are less likely to have a primary care physician (PCP) and more likely to report unmet medical needs or dissatisfaction with their care than the general population.[xxxiv]

Another focus for community understanding is "first responders." The rate of nonfatal, violent crime against persons with disabilities was 1.5 times higher than the rate for persons without disabilities, and 35 percent of individuals with autism have been the victim of a crime, while 23 percent have had interactions with first responders due to wandering or eloping.[xxxv]

Ohio Strengths

- Ohio's Governor signed an Executive Order designating Ohio a "disability inclusion" state. The order called for state agencies to take numerous actions aimed at improving hiring, recruitment, and retention of individuals with disabilities, as well as creating and sustaining a culture of inclusion throughout the workplace.
- A community toolkit was developed to more broadly share ASD Strategies in Action with local groups such as Autism Societies, libraries, movie theaters, and others who have expressed interest in this resource. The toolkit provides everything from marketing materials, video clips, and partnership ideas to share ASD Strategies in Action with communities.
- OCALI hosted a series of community conversations focused on access and inclusion with representatives from hospitality, city and regional planning, architecture, higher education, and religious organizations.
- Ohio passed a Communication Disability law, creating a voluntary self-registry for any individual with a medically diagnosed communication disability, who drives or regularly has someone with a communication disability in their vehicle. This law also includes required training for peace officers, developed in conjunction with disability stakeholders.
- ODH funds the Ohio Disability and Health Program (ODHP), aimed at reducing health disparities for Ohioans with disabilities. ODHP is guided by a Disability Advisory Committee, made up of people with disabilities, families, healthcare professionals, and system partners. Along with their partners, ODHP developed Core Competencies of Disability for Health Care Education to improve training and address bias in the medical community.

Targeted Priorities

The following have been identified as priorities:

1. Outreach to **community partners.**
2. Outreach to **employers.**
3. Outreach to the **medical community.**

LIVE WELL

Knowing how to network and navigate available community resources is fundamental to developing and sustaining effective supports for a successful future.

What We Know

Roughly half of all teens on the autism spectrum live in very low-income households, and one in four autistic teens live in households below the federal poverty level. Approximately 100,000 youth with autism turn 18 each year – meaning 25,000 autistic youth enter adulthood each year with the added difficulties that come with deep poverty, and the need to navigate many resources and systems.[xxxvi]

Over half of young adults with autism are unemployed and unrolled in higher education in the two years after high school—this is lower than any other disability category.[xxxvii] By the age of 25, more than 50% of individuals with ASD have never obtained paid employment.[xxxviii]

Adults with ASD are significantly more likely to have Medicaid coverage and be eligible for Supplemental Security Income (SSI), as well as the use of other public benefits (e.g., food stamps, Temporary Assistance for Needy Families [TANF]), than other groups.[xxxix]

Transportation access affects all areas of life. Many adults with autism want to use public transportation, get a driver's license, or both, as a means to achieve greater independence and community access, but lack the support to do so.[xl] Transportation options are often hard to utilize, too expensive, too limited, or simply unavailable.

In addition to relying on family for most of their transportation needs, almost 90% of young adults with autism live with their parents at some point - a far higher percentage than in the general population of young adults.[xli]

Ohio Strengths

- OOD offers Ohio College2Careers at 15 public colleges and universities in Ohio to ensure students with disabilities have the support they need to complete their degree and/or credential, earn higher wages, and meet the demands of tomorrow's labor market. They have also expanded their pre-employment transition services.
- ODE and OOD collaborate on the Ohio Transition Support Partnership (OTSP). This innovative approach changed the nature and impact of transition services for students with disabilities in Ohio. The Partnership increases the availability of Vocational Rehabilitation (VR) counselors for students with disabilities beginning at age 14 to improve post-school outcomes.
- Ohio launched DB 101, an integrated suite of online tools, information, and training where people with disabilities can directly access plain-language information about work and benefits and health coverage programs. Three calculators have been developed: Work and Benefits, School To Work; Medicaid Buy-In. DB 101 is a resource for families, job seekers, and professionals that can be used to help analyze the impact of employment on an individual's benefits.
- In partnership with DODD, the Ohio State University Nisonger Center established the Smart Home Discovery Place (SHDP). The goal of SHDP is to increase the awareness and understanding of individuals with IDD, their family members as well as providers who support them about smart home technologies and related resources that may be a viable solution for their everyday support needs and might help them to live with greater independence.
- Ohio's 811 Program is a collaboration between DODD, ODM, OMHAS, and the Ohio Housing Finance Agency. The program is targeted to extremely low-income people, who have a disability and qualify for Medicaid, and who are at least 18 years of age, but not more than 61 at move-in.

Targeted Priorities

The following have been identified as priorities:

1. Information and education specific to **employment supports**.
2. Information and education specific to **post-secondary options** (education, training, etc.).
3. Information and education specific to community resources, including **housing and transportation.**

SUSTAIN THE FUTURE

Thoughtful planning and coordination are necessary to uphold broad, but connected, service systems that are responsive to individuals with ASD and their families.

What We Know

Nationally, costs for autism services have reached nearly $270 billion and are estimated to reach $461 billion by 2025. The majority of these costs are for adult services—nearly $200 billion/year.[xlii] While services are many and varied, they are often poorly coordinated, complicated, or duplicative, and people with autism feel the effects across multiple domains: employment, education, health care, social engagement, and independent living.

Federal law requires schools to have a transition plan for every special education student exiting high school—a plan addressing education, employment, and independent living. Nationally, only 58% of youth with autism had a plan by the required age. Income, race, and ethnicity impact this outcome. More Hispanic (77%) and white (60%) young adults received transition planning on time than black young adults (46%). Nearly 60% of those from upper-income households (>$75K) received timely transition planning compared to 33% of those from the lowest-income households (<$25k).[xliii]

Another arena for transition planning is healthcare. People with ASD are less likely to consult with their doctor regarding healthcare transition or to complete tasks or activities related to healthcare transition when compared to individuals without disabilities or with a disability other than ASD.[xliv] They are also less likely to have parents or caregivers with the knowledge to support them in obtaining health insurance as an adult.[xlv]

While families play an essential role in the lives of people with autism, studies have shown many parents are not planning for their futures or the futures of their children. Fewer than half of parents who have a child with a disability make long-term plans—sometimes due to financial constraints or conflicts within the family. Many families say they simply do not have the information to develop a plan. Most families say they do not plan because of the lack of employment, residential, or other services that will meet their family member's needs.[xlvi]

Ohio Strengths

- One of the ongoing efforts of the Employment First Task Force is developing Multi Agency Planning (MAP) teams to improve outcomes for transition youth. Agencies, schools, and providers in many counties have come together to work as a local interagency group to support youth and adults with intellectual and developmental disabilities to access community members and employment. Many county teams developed and signed local interagency agreements that outline common goals and priorities to guide practice and collaborative work.
- OMHAS developed a Transition Toolkit through their ENGAGE project which includes information on crisis planning, education, finances (including estate planning), guardianship, healthcare, housing, and transportation.
- OMHAS has also done extensive work on developing systems of care throughout Ohio and making wraparound available therein, with the reducing stress, confusion, and duplication, and improving outcomes for youth and families.
- DODD has begun providing additional information to families through their "5 Things" series. Topics include: Pooled Trust; Trusts; Special Needs Trusts; STABLE Accounts; Guardianship (and a Guardianship Toolkit);

Targeted Priorities

The following have been identified as priorities:

1. **"Adult life"** as a focus of transition (i.e., healthcare, housing, transportation, not only education/employment).
2. **Coordination** of assessments, plans, and services—across settings, service sectors, and the lifespan.
3. **Long-term planning** for families.

ENDNOTES

[i] Abigail Issarraras, Johnny L. Matson, Maya Matheis & Claire O. Burns (2018): Differences in Developmental Concerns of Young Children with Autism Spectrum Disorder Across Racial/Ethnic Groups, Developmental Neurorehabilitation, DOI: 10.1080/17518423.2018.1504828

[ii] Julia R. Henly & Gina Adams (2018): Increasing Access to Quality Child Care for Four Priority Populations. Urban Institute. **https://www.urban.org/sites/default/files/publication/99150/increasing_access_to_quality_child_care_for_four_priority_populations_report_3.pdf**

[iii] OCALI. ADEP Report (2018). **https://www.ocali.org/up_doc/ADEPDataBrief2018.pdf**

[iv] Cristina Novoa (2020): The Child Care Crisis Disproportionately Affects Chidlren with Disabilities. Center for American Progress. **https://www.americanprogress.org/issues/early-childhood/reports/2020/01/29/479802/child-care-crisis-disproportionately-affects-children-disabilities/**

[v] Kathryn A. Smith, Jean-G. Gehricke, Suzannah Iadarola, Audrey Wolfe, Karen A. Kuhlthau (2019). Disparities in Service Use Among Children With Autism: A Systematic Review. Pediatrics Apr 2020, 145 (Supplement 1) S35-S46; DOI: 10.1542/peds.2019-1895G

[vi] Children's Hospital Association (2017). Pediatric Workforce Shortages Persist. **https://www.childrenshospitals.org/- /media/Files/CHA/Main/Issues_and_Advocacy/Key_Issues/Graduate_Medical_Education/Fact_Sheets/CHGME_Workforce_Shortage_Fact_Sheet.pdf**

[vii] Alexandra C. Kirsh, Andrea R. S. Huebner, Sunil Q. Mehta, et al., (2019): Association of Comorbid Mood and Anxiety Disorders with Autism Spectrum Disorder. JAMA Pediatr 2019 Dec 2; [e-pub]. **https://doi.org/10.1001/jamapediatrics.2019.4368**

[viii] Luther G. Kalb, Elizabeth A. Stuart, Brian Freedman, Benjamin Zablotsky, Roma Vasa (2012): Psychiatric-Related Emergency Department Visits Among Children With an Autism Spectrum Disorder. Pediatric Emergency Care: December 2012 - Volume 28 - Issue 12 - p 1269-1276 doi: 10.1097/PEC.0b013e3182767d96

[ix] Jessica E. Rast, Paul T. Shattuck, Anne M. Roux, Kristy A. Anderson and Alice Kuo (2018). The Medical Home And Health Care Transition For Youth With Autism. Pediatrics,141(Supplement 4), S328-S334.

[x] Ann V. Kirby, Amanda V. Bakian, Yue Zhang, Deborah A. Bilder, Brooks R. Keeshin, Hilary Coon (2019). A 20-year study of suicide death in a statewide autism population. Autism Research, 12(4), 658-666.

[xi] OSEP Fast Facts: Children Identified with Autism (2020). **https://sites.ed.gov/idea/osep-fast-facts-children-with-autism-20/**

[xii] Freddie W. Litton, Anthony R. Rotatori, Rita Coombs-Richardson, and Rachel Martinez, "Preparation for Teachers for Students with Autism Spectrum Disorders: A Call for Quality and Quantity." American Jounral of Educational Research, vol. 5, no 2. (2017): 225-230. doi: 10.12691/education-5-2-19.

[xiii] ibid

xiv OSEP Fast Facts: Children Identified with Autism (2020). **https://sites.ed.gov/idea/osep-fast-facts-children-with-autism-20/**

[xv] Anne M. Roux, Paul T. Shattuck, Jessica E. Rast, Julianna A. Rava, and Kristy A. Anderson. (2015) National Autism Indicators Report: Transition into Young Adulthood. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University.

[xvi] Paul T. Shattuck, Jessica E. Rast, Anne M. Roux, Kristy A. Anderson, Teal Benevides, Tamara Garfield, Elizabeth Hassrick McGhee, and Alice Kuo. (2018) National Autism Indicators Report: High School Students on the Autism Spectrum. Philadelphia, PA: Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University.

[xvii] Anne M. Roux, Paul T. Shattuck, Jessica E. Rast, Julianna A. Rava, and Kristy A. Anderson. (2015) National Autism Indicators Report: Transition into Young Adulthood. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University.

[xviii] ibid

[xix] Tony Gentry, Richard Kriner, Adam Sima, Jennifer McDonough, and Paul Wehman. (2015). Reducing the Need for Personal Supports Among Workers with Autism Using an iPod Touch as an Assistive Technology: Delayed Randomized Control Trial. Journal of autism and developmental disorders, 45(3), 669-684.

[xx] The Ohio State University Nisonger Center. Ohio Technology Project. Background. **https://nisonger.osu.edu/adult/resources/technology-project/**

[xxi] Kristy A. Anderson, Jessica E. Rast, Anne M. Roux, Tamara Garfield, and Paul T Shattuck. (2020) National Autism Indicators Report: children on the autism spectrum and family financial hardship. Philadelphia, PA: Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University.

[xxii] ibid

[xxiii] S. Hodgetts, D. McConnell, L. Zwaigenbaum, and D. Nicholas. (2017). The impact of autism services on mothers' psychological wellbeing. Child: care, health and development, 43(1), 18-30.

[xxiv] Kristy A. Anderson, Jessica E. Rast, Anne M. Roux, Tamara Garfield, and Paul T Shattuck. (2020) National Autism Indicators Report: children on the autism spectrum and family financial hardship. Philadelphia, PA: Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University.

[xxv] ibid

[xxvi] ibid

[xxvii] Daniel W. Hoover, and Joan Kaufman. (2018). Adverse childhood experiences in children with autism spectrum disorder. Current opinion in psychiatry, 31(2), 128–132. https://doi.org/10.1097/YCO.0000000000000390

[xxviii] Christophe Maiano, Claude L. Normand, Marie-Claude Salvas, Gregory Moullec, and Annie Aimé. (2016). Prevalence of school bullying among youth with autism spectrum disorders: A systematic review and meta-analysis. Autism research, 9(6), 601-615.

[xxix] Anne M. Roux, Paul T. Shattuck, Jessica E. Rast, Julianna A. Rava, and Kristy A. Anderson. (2015) National Autism Indicators Report: Transition into Young Adulthood. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University.

[xxx] Eilidh Cage, Jessica Di Monaco, and Victoria Newell. (2018) Experiences of Autism Acceptance and Mental Health in Autistic Adults. J Autism Dev Disord 48, 473–484. https://doi.org/10.1007/s10803-017-3342-7

[xxxi] Anne M. Roux, Paul T. Shattuck, Jessica E. Rast, Julianna A. Rava, and Kristy A. Anderson. (2015) National Autism Indicators Report: Transition into Young Adulthood. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University.

[xxxii] Angela Marie Mai. (2019). Hiring Agents' Beliefs: A Barrier to Employment of Autistics. SAGE Open, 9(3), 2158244019862725.

[xxxiii] Kristy A. Anderson, Jessica E. Rast, Anne M. Roux, Tamara Garfield, and Paul T Shattuck. (2020) National Autism Indicators Report: children on the autism spectrum and family financial hardship. Philadelphia, PA: Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University.

[xxxiv] Youssra Saqr, Erika Braun, Kyle Porter, Debra Barnette, and Christopher Hanks. (2018). Addressing medical needs of adolescents and adults with autism spectrum disorders in a primary care setting. Autism, 22(1), 51-61.

[xxxv] The Ohio State University. Office of Outreach and Engagement. First Responder Education: How to Work with People with Communication Disorders. Engaged Scholars, v. 7 (2019)

[xxxvi] Paul T. Shattuck, Jessica E. Rast, Anne M. Roux, Kristy A. Anderson, Teal Benevides, Tamara Garfield, Elizabeth Hassrick McGhee, and Alice Kuo. (2018) National Autism Indicators Report: High School Students on the Autism Spectrum. Philadelphia, PA: Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University.

[xxxvii] Harmuth, E., Silletta, E., Bailey, A., Adams, T., Beck, C., & Barbic, S. P. (2018). Barriers and Facilitators to Employment for Adults With Autism: A Scoping Review. Annals of International Occupational Therapy, 1(1), 31-40.

[xxxviii] ibid

[xxxix] Jean P. Hall, and Noelle K. Kurth. (2019). A Comparison of Health Disparities Among Americans With Intellectual Disability and/or Autism Spectrum Disorder and Americans With Other Disabilities. Inclusion, 7(3), 160-168.

[xl] Andrea Lubin, and Cecilia Feeley. (2016). Transportation Issues of Adults on the Autism Spectrum: Findings from Focus Group Discussions. Transportation Research Record, 2542(1), 1–8. **https://doi.org/10.3141/2542-01**

[xli] Anne M. Roux, Paul T. Shattuck, Jessica E. Rast, Julianna A. Rava, and Kristy A. Anderson. (2015) National Autism Indicators Report: Transition into Young Adulthood. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University.

[xlii] ibid

[xliii] ibid

[xliv] Zablotsky, B., Rast, J., Bramlett, M. D., & Shattuck, P. T. (2020). Health Care Transition Planning Among Youth with ASD and Other Mental, Behavioral, and Developmental Disorders. Maternal and Child Health Journal, 1-9.

[xlv] ibid

[xlvi] Clausen House. **http://clausenhouse.org/2014/2018/02/23/many-parents-not-planning-for-future-of-children-with-disabilities-according-to-new-study/**

Pursuing Quality Lives 2020

www.iwg-autism.org