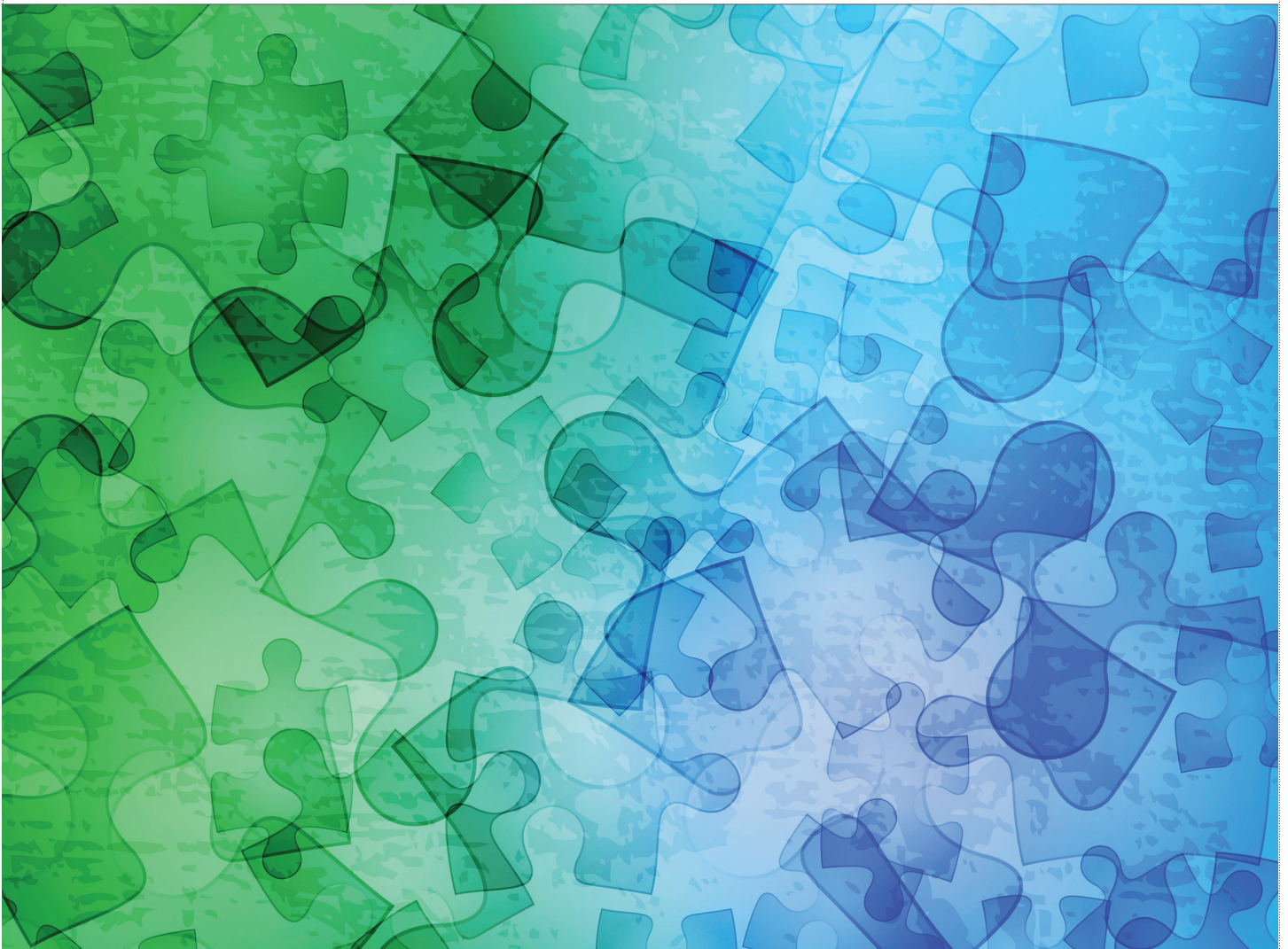


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# An Exploration of Fiscal Resources and Systems Needs related to Autism Spectrum Disorder Services and Supports in Ohio:

Fiscal Analysis and Parent/Caregiver Interview Results



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## Executive Summary

In order to advocate for policies that align and leverage funding streams in service to the needs of families and individuals affected by autism spectrum disorders (ASD), the Educational Service Center of Central Ohio (ESCCO) and the Center for Systems Change at the Ohio Center for Autism and Low Incidence disorders (OCALI) commissioned the College of Social Work at The Ohio State University to conduct a fiscal analysis of ASD funds and to explore parent/caregiver perceptions of the ASD service delivery system in Ohio. There were two purposes of this work:

- To identify federal and state funding streams that are available or may be used to support autism spectrum disorders in Ohio and
- To explore stakeholder (particularly parents/caregivers) experiences with the ASD service delivery system and related informal social supports.

The findings from both research components provide insights into ways in which the ASD service delivery system might be improved, as fiscal mapping data inform resource investments and consumer perspectives' drive continuous improvements.

Specifically, 390 line items across 15 state departments were identified as potential funding sources that might be leveraged to support services and supports across the autism spectrum. Of the 390 line items, 3 were identified that primarily support ASD services, including: the Interagency Workgroup on Autism, Foundation Funding, and Help Me Grow. Seventy-nine line items that support individuals with disabilities were identified, as well as 142 line items that might be leveraged in support of ASD services in the future.

A content analysis of the primary program and service areas targeted within each budget line item was then completed. A total for 74 program and service theme areas emerged. To sharpen focus, funds were further mapped according to 10 priority program and service areas critical to the ASD service delivery system (as identified by OCALI leaders). These 10 areas included: prenatal and maternal health, early intervention and child care, nutrition, health education, awareness, and referrals, outpatient behavioral and mental health care, career-technical education, job training, vocational rehabilitation, healthcare workforce development, and educator workforce development. A full list of line items, their fund type, and their fiscal year allocations, as well as a document with line item descriptions, are provided at the following link: <http://csw.osu.edu/cayci/currentprojects/ocali/index.cfm>.

Last, gaps in funding were identified, such as support for social skills training and peer interaction, young adult transitions, employment supports, life span supports, professional development, and technology. Line items were identified through the fiscal mapping that might support future funding in these gap areas to improve funding across the life span.

Additionally, interviews with stakeholders detail parent/caregiver perceptions of the ASD service delivery system, as well as experiences with informal social supports. These findings were further validated through focus groups and interviews with other relevant stakeholders. Parents/caregivers who were interviewed employed a number of coping strategies when navigating the service delivery system. Coping strategies included themes such as making life changes and sacrifices, accessing varying levels of social support, displaying ongoing determination and persistence when faced with various obstacles (i.e., unresponsive providers), engaging in advocacy and empowerment-oriented practices, staying positive, and trying different strategies to determine what works for their child and family. In relation to informal social supports, participants reported that parent/caregiver support groups were helpful during the early stages of diagnosis as they were developing coping strategies, needing help with the identification of resources, and wanting connections with other parents/caregivers. Many participants, however, expressed that these groups were often too negative and/or overly cynical. Participants reported disconnecting from groups overtime in order to maintain a positive outlook.

Overall, the parents/caregivers who participated in the study described both positive (e.g., coordination and collaboration with service providers; provider willingness to learn) and negative experiences (e.g., delays in getting a diagnosis; regional disparities) with service access and delivery. Positive experiences were mentioned more often than negative ones and include themes such as when: 1) there was open and flexible communication with service providers; 2) providers were responsive, willing to learn, and valued parents/caregivers opinions; 3) parents/caregivers reported that either they or someone they knew had insider knowledge; and 4) parents/caregivers were able to piece together various funding sources to obtain needed services for their child with an ASD diagnosis. Common factors related to negative experiences included when there were: 1) delays in receiving an initial diagnosis; 2) non-responsive and/or unqualified service providers; 3) system disconnects (i.e. between initial diagnosis, referrals to other types of services and information about how to obtain financial assistance for services); 4) the lack of needed services (i.e. parents/caregivers reported that some counties/geographic areas have fewer or no resources); and further lack of financial means to obtain needed services. Furthermore, parents/caregivers also detailed gaps/needs. Key themes include services for young adults (e.g., independent living planning and employment training and support), extended school day, social skills and emotional regulation, quality service providers/information, extended school services, sensory equipment, and community awareness and education (particularly in rural areas).

Together findings point to several action steps and priorities. The fiscal analysis calls for:

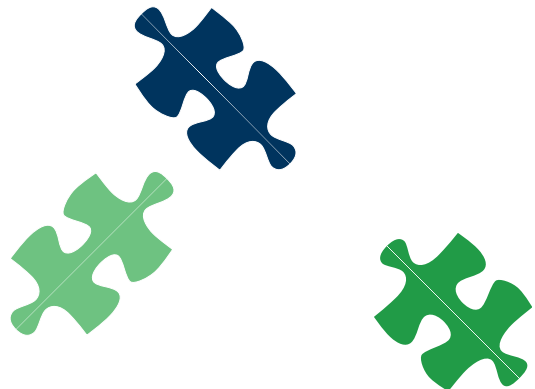
- Continued promotion of cross-agency collaboration in program development, administration, and grant writing at the state-level through the Interagency Work Group on Autism.
- The consideration of funding integration particularly in relation to the 3 primary ASD line items and inclusion of individuals with ASD in disability-related (e.g., Vocational Rehabilitation) and general population funding streams (e.g., Unemployment).
- The exploration of identified funding streams that could be leveraged to support ASD across the lifespan and continuum of services, particularly in areas where there are gaps such as technology, employment, and professional development.
- Additional advocacy efforts that leverage funding streams and policy structures in order to improve ASD services and eliminate disparities [e.g., health insurance coverage, regional

funding and service disparities (e.g., county disparities in eligibility, funding, and service capacity)] in ASD service delivery in Ohio.

Parents/caregivers experiences document action steps related to:

- The need for clear, concise, and coordinated communication to parents/caregivers about how to access services and what types of financial supports are available to support individuals with ASD.
- The improvement of collaboration and communication among parents/caregivers, service providers, and others involved in supporting individuals on the spectrum. To facilitate continuity, providers should communicate knowledge of needs and strategies/services that worked in one stage that should be transitioned to the next.
- The enhancement of professional development and pre-service training on ASD for educators, medical professionals, and others who work with individuals on the spectrum, particularly in relation to increasing awareness of the early signs of ASD.
- Additional inquiry into the design and implementation of parent/caregiver support groups and other informal support activities so that improvements in these social supports may be made.
- Further research with ASD service providers to obtain their perspectives on the current service delivery system in relation to gaps, barriers, and suggestions for improvement.

In conclusion, we are hopeful these findings promote action towards improving the system of supports in Ohio for individuals with ASD, as well as improving the experiences of parents/caregivers who serve as one key informal structure within this system. For further information related to this report, please contact Dawn Anderson-Butcher ([anderson-butcher.1@osu.edu](mailto:anderson-butcher.1@osu.edu)).



# Introduction

In March 2012, the Centers for Disease Control (CDC) issued its latest report, estimating that 1 in every 88 children and 1 in 54 boys in the United States have autism spectrum disorders (ASD; CDC, 2012). ASD rates have soared over the last three decades, as autism was believed to affect just 1 in 2,000 children in the 1970s (CDC, 2009; CDC, 2012). Youth and young adults with ASD have multiple complex needs leading to more outpatient and physician visits and greater education and school-based service utilization than youth and young adults with non-ASD diagnoses (Liptak et al., 2006; Mandell et al., 2005). As the prevalence of youth and young adults with ASD increases, demands on the service delivery system are growing and intensifying (Dymond, Gilson, & Myran, 2007).

Given the rising prevalence of ASD and associated service demands, state and local governments and health and social service agencies are faced with growing numbers of individuals and families living with ASD and in need of services. Among the needed services are education on the signs of autism, access to expert diagnosticians, early screening and intervention, services across the lifespan, and transition supports as individuals move into employment and independent living (Autism Society of Ohio Press Release, April 2012). A primary challenge for the service delivery system involves ensuring that youth and young adults with ASD and their families actually receive the interventions that they require for their unique and multiple needs (McWilliam, Young, & Harville, 1996). This becomes an even more difficult task in today's economic times. It is clear: As the number of individuals in need of ASD services is increasing, public revenues are decreasing (Mauch, Pfefferle, Booker, Pustell, & Levin, 2011). Subsequently, states are challenged to meet the growing demand for publicly funded services (Mauch et al., 2011). In order to meet this demand, it is necessary to explore the extent to which the current service delivery system meets the needs of youth and young adults with ASD.

This research initially uses fiscal mapping to investigate the various state and federal dollars that support (or could support) services for individuals with ASD in Ohio. Fiscal maps are useful as they examine how funds are used, as well as offer an account of all federal and state expenditures on a particular area of interest such as ASD (Connors-Tadros & Lesko, 2011). Fiscal maps also identify major funding sources, locate where the funding comes from, and consider how fiscal resources can be effectively leveraged (Connors-Tadros & Lesko, 2011). In the end, fiscal maps may be used to increase coordination, maximize funding opportunities, and advocate for additional investments (Connors-Tadros & Lesko, 2011). The fiscal analysis done here identifies that the various line-items in the state budget that may be used, aligned, and leveraged in support of ASD services. The analysis also points to gaps/needs in funding for priority areas within the service delivery continuum.

Additionally, to explore the extent to which the ASD service delivery system meets family and individual needs, it is important to hear the perspectives of the ASD service delivery system as provided by consumers. For instance, the autobiographies of many adults with ASD demonstrate insight into the obstacles to receiving appropriate supports (Grandin, 1995; Kluth, 2004). Parents/caregivers, however, are often the primary source of information about their child's needs since many youth and young adults with ASD have difficulty expressing their needs for support (Dymond et al., 2007). Here we specifically examine parent/caregiver perceptions of the ASD service delivery system and related informal supports.

Past research has also examined parents/caregiver perceptions. For example, a number of studies examine parent/caregiver perceptions of needs for services for their child (Spann, Kohler, & Soenksen, 2003; Whitaker, 2002), difficulties experienced when obtaining services (Kohler, 1999; Sperry et al., 1999), the availability and accessibility of services (Little, 2003), the helpfulness of services (Little, 2003), and the satisfaction with services (Spann et al., 2003; Starr, Foy, & Cramer, 2001). Overall, the results from these studies suggest parents/caregivers have difficulty accessing services and locating needed services (Kohler, 1999; Little, 2003; Spann et al., 2003). Further information is needed from parents/caregivers; however, in relation to the types of funding, services, and supports (both informal and formal) they utilize to support their children. Ultimately, additional information about parents'/caregivers' perceptions of the service delivery system as well as experiences with informal support systems will allow for improvements in the existing service delivery system to be made in the future.

## Study Overview

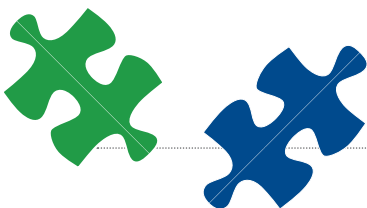
In order to advocate for policies that drive the alignment and leveraging of funding streams in service to the needs of families and individuals affected by ASD, the Educational Service Center of Central Ohio (ESCCO) and the Ohio Coalition for Autism and Low Incidence disorders (OCALI) commissioned The Ohio State University College of Social Work to conduct a fiscal analysis of autism spectrum disorder funds and to explore parent/caregiver perceptions of the autism spectrum disorder service delivery system in Ohio. The research had two purposes:

- To identify federal and state funding streams that are available or may be used to support autism spectrum disorders in Ohio and
- To explore stakeholder (particularly parents/caregivers) experiences with the ASD service delivery system and related informal social supports.

The first component of the study involves a fiscal mapping to identify the various funding mechanisms available or that might be leveraged to fund various ASD services in Ohio. A broadened understanding of how these funding streams are aligned and accessed across multiple systems is helpful for making the most effective use of the current resources and for advocating for future policies that support families and individuals impacted by ASD.

The second component of the study centers on the exploration of parent/caregiver perceptions of the ASD service delivery system and related informal social supports. A deepened understanding of the challenges parents/caregivers face, as well as knowledge of the formal and informal resources they leverage, will inform the delivery of more responsive services and supports in the future. Both research purposes aim to drive future capacity building and policy advocacy to support people with ASD, parents/caregivers, providers, and others working in this area.

This report is organized as follows. Part I overviews the methods and results related to the fiscal analysis. Part II describes the findings from the parent/caregiver interviews. Part III synthesizes the findings across the 2 research components and concludes with practice, policy, and research implications and future action steps and priorities.







## PART I:

# A Fiscal Analysis of Federal and State Funding Streams to Support ASD Related Services

The purpose of the first phase of the research was to identify federal and state funding streams that support or could be leveraged to support ASD related services. This work was guided by several key research questions, including:

- What are the diverse funding streams at the federal and state level that are available in Ohio to support autism spectrum disorders for youth and adults?
- What funding streams support professional development and technical assistance to professionals who work with individuals with autism spectrum disorders?
- Who manages the identified funding streams (i.e., state agency, etc)?
- What are potential funding streams that could be leveraged to support autism spectrum disorders?

## Research Procedures

The line items in 15 state department's 2012-2013 biennial state budgets, as outlined in the state Greenbooks produced by the state Legislative Service Commission (LSC), were examined. These state departments were selected for inclusion in consultation with OCALI. Inclusion requirements focused on whether the department housed funds relevant to supporting individuals with disabilities across the life span.

Once selected, enacted budget line items in each state department's Greenbook were reviewed. Relevant budget line items were selected for inclusion in the analyses if they were or could potentially be leveraged to support ASD related services in the following areas: early education, primary and secondary education, health and mental health care, employment, postsecondary education, family support (e.g., financial services), home and community-based services, residential services, protection and advocacy, rehabilitation and corrections (adult and juvenile), and department operations. Researchers were over-inclusive in the selection of line items, thus ensuring comprehensiveness in the number of line items reviewed. Please note that all federal programs have a state budget line item if the state receives funds associated with that identified federal program.

Once selected, budget line items were reviewed in relation to their purpose, program description, eligible applicants and beneficiaries, type of funds, and funding allocations. Additionally, funds were described in relation to the type of funds (where it was derived from such as tax dollars, federal grants, etc) in the state budget: general revenue fund (GRF), general service fund (GSF), federal special revenue fund (FED), and state special revenue (SSR; Padgette, 2003). Please note that each state department budget receives funding from these 4 fund groups, but varies significantly in the degree to which it relies on a particular fund group. This composite of funding is important because the type of fund group (i.e. GRF) provides some indication as to the

mechanism of allocation to school districts, county departments, mental health boards, and community agencies.

In total, 390 line items were identified as potential funding sources that might be leveraged to support services and supports across the autism spectrum. The line items served as the raw data. Table 1 lists the 15 state departmental budgets and the number of the line items per each department examined in this study. A full list of line items, their fund type, and their fiscal year allocations, as well as a document with line item descriptions, are provided at the following link: <http://csw.osu.edu/cayci/currentprojects/ocali/index.cfm>

## Data Analysis

Using an inductive approach (Patton, 1990), 2 researchers worked independently to code each line item using a line item coding sheet. The line item coding sheet included information on the primary programs and services supported by the line item, whether the line item supports the general population, a special population, or both, the line item's target age group, and the special population targeted by the fund (e.g., low income).

Next, a content analysis of the primary program and service areas targeted within each budget line item was completed. More specifically, analyses focused on identifying the manifest content of each line item and its respective words (e.g., "autism," "developmental disabilities," "home and community-based services"), especially those that were indicative of investment (Babbie, 2007). Conceptual themes emerged through the data coding process, as recommended in qualitative research (Glaser & Strauss, 1967; Lincoln & Guba, 1985; Miles & Huberman, 1994).

As with any content analysis, a critical component throughout the research process involves validating the results and ensuring the reliability of the findings. As such, several credibility checks (Barker & Pistrang, 2005; Miles & Huberman, 1994) were conducted in order to establish trustworthiness and ensure integrity of the data analysis. To enhance reliability, 2 independent researchers reviewed each selected line item description. When categorizations differed, the 2 researchers worked together to reach consensus on the identification of theme area. Overall, the researchers reached agreement on the themes. Additionally, funds were reviewed with government and OCALI leaders to check the validity of the findings.

Following the content analysis, themes were reviewed with OCALI staff to enhance the validity of the emergent theme areas. From that review of theme areas, OCALI staff selected 10 of the emergent theme areas of particular interest to the mission of OCALI. These 10 areas included: prenatal and maternal health, early intervention and child care, nutrition, health education, awareness, and referrals, outpatient behavioral and mental health care, career-technical education, job training, vocational rehabilitation, healthcare workforce development, and educator workforce development. The researchers then identified and reviewed the line items within those theme areas as potential funds to leverage in support of ASD services.



**Table 1. State Departments and Line Item Number**

State Department	Number of Line Items	%
Department of Job and Family Services	75	19%
Department of Health	67	17%
Board of Regents	54	14%
Department of Education	35	9%
Department of Mental Health	34	9%
Department of Rehabilitation and Corrections	26	7%
Department of Developmental Disabilities	20	5%
Rehabilitation Services Commission	15	4%
Department of Youth Services	15	4%
Legal Rights Services	14	4%
Department of Alcohol and Drug Addiction Services	11	3%
Department of Aging	10	3%
Ohio State School for the Blind	6	2%
Ohio State School for the Deaf	6	2%
Commission on Minority Health	2	<1%
<b>Total</b>	<b>390</b>	

## Findings

The 390 line items across the 15 state departments were reviewed. Half of the line items reviewed were housed in the Department of Job and Family Services, Department of Health, and Board of Regents. A third of the line items were in the Departments of Education, Mental Health, Rehabilitation and Corrections, and Developmental Disabilities. Of the 390 line items, only 3 line items specifically reference ASD in the line item descriptions and 79 line items reference providing services and support to individuals with a disability, in general.

The 3 line items that specifically reference ASD are illustrated in Table 2. These 3 line items are housed in 3 different state departments, including the Department of Developmental Disabilities, the Department of Education, and the Department of Health. These 3 line items primarily support early intervention and identification, education, and interagency collaboration. More specifically, the Interagency Workgroup on Autism line item is devoted to collaboration and coordination of policy around autism spectrum disorder supports; however both the Foundation Funding line item and Help Me Grow line item fund several programs, including specific earmarks for autism spectrum disorder supports. Foundation Funding and Help Me Grow are both funded with GRF that come from state revenue such as tax dollars while the Interagency Workgroup on Autism is funded by a newly established fund (Fund 5JX0) in the state treasury. Workgroup members may contribute to the fund to support workgroup activities. This line item did not exist in FY11 but the expenditure did.

Table 2. Line Items Specific to Autism Spectrum Disorders<sup>1</sup>

Line Item Name	FundType	FY11	FY12	FY12 % Change	FY13	FY13 % Change	Description
<b>DEPARTMENT OF DEVELOPMENTAL DISABILITIES</b>							
Interagency Workgroup on Autism	Fund 6JX0	\$0	\$45,000	N/A	\$45,000	0.00%	Improves the coordination of efforts to address the needs of individuals with autism spectrum disorders and their families; distributes information on autism
<b>DEPARTMENT OF EDUCATION</b>							
Foundation Funding: Autism Scholarship Program	GRF	\$5,257,922,850	\$5,536,347,861	5.30%	\$5,610,290,686	1.34%	Gives parents/caregivers the option to seek services for their child with a registered private provider, rather than the child's resident school district
<b>DEPARTMENT OF HEALTH</b>							
Help Me Grow: The Developmental Autism Screening Program	GRF	\$46,391,346	\$33,673,545	-7.47%	\$33,673,987	0.00%	Funds early identification of infants and toddlers with developmental delays and disabilities; Provides assistance with services and supports; Covers developmental, social-emotional, vision, and hearing screenings.

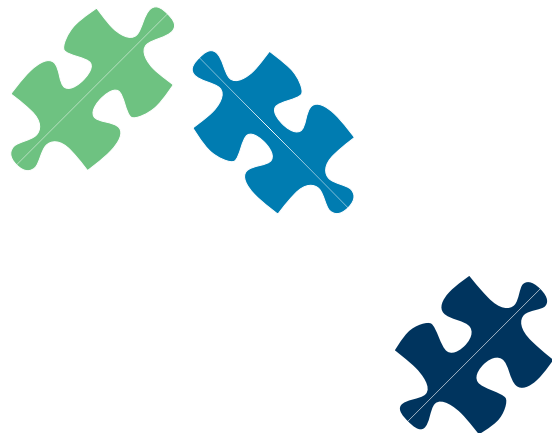
<sup>1</sup> The fiscal year allocations provided in this table were obtained from each state department's respective Legislative Service Commission Greenbook (2012) retrieved from <http://www.lsc.state.oh.us>

Although ASD was only explicitly mentioned in 3 line items, 79 line items support services for individuals with disabilities, in general. The number of disability-related line items per each state department is illustrated in Table 3. The majority of these line items were housed in the Department of Developmental Disabilities (n=20), Rehabilitation Services Commission (n=15), and Legal Rights Services (n=12). These 79 line items primarily support waiver programs (e.g., home and community-based services), employment support, protection and advocacy services, special education, cash assistance, and health care. All 79 disability-related line items are presented at <http://csw.osu.edu/cayci/currentprojects/ocali/index.cfm>.

**Table 3. Number of Disability-Related Line Items Across State Departments**

State Department	Number of Disability Related Line Items	%
Department of Developmental Disabilities	20	25%
Rehabilitation Service Commission	15	19%
Legal Rights Services	12	15%
Department of Health	10	13%
Department of Job and Family Services	8	10%
Department of Education	8	10%
Department of Mental Health	5	6%
Board of Regents	1	1%
<b>Total</b>	<b>79</b>	

Table 4 highlights the disability-related line items with the largest dollar investment in each of the 8 state departments. Across the 8 departments, the largest dollar investments were Medicaid Waiver-Federal (Department of Developmental Disabilities), Individuals with Disabilities Education Act (Department of Education), and Health Care/Medicaid (Department of Job and Family Services). Medicaid Waiver line items enable individuals with developmental disabilities to remain in their homes or community-based settings by providing them with services and support to maximize their quality of life while also ensuring their health and safety. The Health Care/Medicaid line item covers health care services for individuals who receive Medicaid. The IDEA line item in addition to early education special education line items (e.g., Early Childhood Education) fund schools to support the costs associated with individual special education students.



**Table 4. Disability-Related Line Items with the Largest Dollar Investment by Department<sup>1</sup>**

Line Item Name	FundType	FY11	FY12	FY12 % Change	FY13	FY13 % Change	Description
<b>DEPARTMENT OF DEVELOPMENTAL DISABILITIES</b>							
Medicaid Waiver – Federal	FED	\$741,460,889	\$866,566,007	16.80%	\$985,566,007	13.70%	Covers home and community-based Medicaid waiver services and administration of services
<b>REHABILITATION SERVICES COMMISSION</b>							
Federal – Vocational Rehabilitation	FED	\$99,058,744	\$103,160,426	4.14%	\$103,150,102	-0.01%	Funds vocational rehabilitation services
<b>LEGAL RIGHTS SERVICE</b>							
Protection and Advocacy Developmentally Disabled	FED	\$1,101,818	\$1,662,991	50.93%	\$415,748	-75.00%	Protects and advocates for the human and civil rights of people with developmental disabilities in developmental centers, schools, and communities
<b>DEPARTMENT OF EDUCATION</b>							
Individuals with Disabilities Education Act	FED	\$423,753,393	\$443,170,050	4.50%	\$443,170,050	0.00%	Assists in the provision of a free and appropriate education to all children with disabilities from age 3 to 21
<b>DEPARTMENT OF JOB AND FAMILY SERVICES</b>							
Health Care / Medicaid	GRF/FED	\$10,453,009,198	\$11,843,769,396	13.30%	\$13,118,813,544	10.70%	Reimburses health care providers for covered services (e.g., physician services, prescription drugs) to Medicaid recipients
<b>DEPARTMENT OF HEALTH</b>							
Maternal Child Health Block Grant <sup>2</sup>	FED	\$21,538,838	\$27,068,886	25.67%	\$27,068,886	0.00%	Improves access to maternal and child health services to reduce infant mortality preventable diseases, and handicapping conditions among children; health, rehabilitative, and other services

Line Item Name	Fund Type	FY11	FY12	FY12 % Change	FY13	FY13 % Change	Description
<b>DEPARTMENT OF MENTAL HEALTH</b>							
Office of Support Services	GSF	\$105,644,796	\$129,770,770	22.84%	\$129,779,822	0.01%	Purchases raw and prepared bulk food items and wholesale pharmaceuticals on behalf of certain state facilities and community agencies
<b>BOARD OF REGENTS</b>							
Student Support Services	GRF	\$0	\$632,974	N/A	\$632,974	0.00%	Supports Ohio's public colleges and universities that have high concentrations of disabled students and incur disproportionate costs in providing instructional and related services to disabled students (e.g., not taking, counseling, transportation services)

<sup>1</sup> The fiscal year allocations provided in this table were obtained from each state department's respective Legislative Service Commission Greenbook (2012) retrieved from <http://www.lsc.state.oh.us>

<sup>2</sup> The Maternal Child Health Block Grant line item is the second largest investment related to disabilities in the Department of Health. The Help Me Grow line item is the largest and is not displayed here because it is showcased in Table 2.

In addition to funds specific to ASD and disabilities, additional funds in the state budget might be leveraged to support programs and services for individuals with ASD and their families. The content analysis identified key program and service areas that the selected line items support. From the content analysis of the budget line item language, 74 theme areas emerged. Eleven of the theme areas consist of line items that support departmental operations (e.g., education, developmental disabilities), 62 theme areas consist of line items that support state and federally funded services and supports for individuals across the life span in a variety of areas (e.g., health, early intervention and day care, home and community-based services), and 1 theme area, collaboration, includes line items that refer to or require interagency coordination and collaboration in the delivery of services.

The theme areas and the number of line items per theme area are illustrated in Table 7 (Appendix A). The theme areas with 25 or more line items included: parent/family support (n=37 line items), home and community-based supports (n=35 line items), job training, workforce development, and unemployment (n=26 line items), and nutrition (n=25 line items). The theme areas with 20 or more line items included: child and adult protective services (n=24 line items), collaboration (n=24 line items), health: treatment (n=23 line items), health: disease and injury prevention (n=21 line items), college awareness and access (n=21 line items), and early intervention and child care (n=20 line items).

Following a review of the 74 theme areas, OCALI staff selected 10 theme areas of particular interest to the mission of OCALI. The ten areas included: prenatal and maternal health, early intervention and child care, nutrition, health education, awareness, and referrals, outpatient behavioral and mental health care, career-technical education, job training, vocational rehabilitation, healthcare workforce development, and educator workforce development. The researchers identified and reviewed the line items within those theme areas as potential funds to leverage in support of ASD services. This process resulted in 142 line items that could be potentially leveraged across the 10 theme areas. Select line items are described in Table 5. The line items displayed were selected because they have the largest dollar allocation within each particular theme/priority area.

In summary, a number of line items across multiple life domains could be explored for their leveraging potential in relation to ASD services and supports and 10 such line items with the largest dollar investment are illustrated in Table 5.

**Table 5. Line Items to Leverage in Relation to Priority Areas<sup>1</sup>**

Priority Area & Line Item	Fund Type	FY11	FY12	FY12 % Change	FY13	FY13 % Change	Description
<b>PRENATAL AND MATERNAL HEALTH</b>							
The Maternal and Child Health Block Grant	GRF	\$21,538,838	\$27,068,886	25.67%	\$27,068,886	0.00%	Improves access to maternal and child health services to reduce handicapping conditions among children; health, rehabilitative, and other services
<b>EARLY INTERVENTION &amp; CHILD CARE</b>							
TANF Block Grant	FED	\$781,745,694	\$727,968,260	-6.88%	\$727,968,260	0.00%	Covers publicly funded child care
<b>NUTRITION</b>							
Federal School Lunch	FED	\$317,998,269	\$327,516,539	2.99%	\$3,337,323,792	2.99%	Provides school lunch
<b>HEALTH EDUCATION, AWARENESS, &amp; REFERRALS</b>							
Women, Infants, and Children (WIC)	FED	\$239,855,705	\$308,672,689	28.69%	\$308,672,689	0.00%	Offers nutritious foods, education, and support, health care referrals through local agencies
<b>BEHAVIORAL &amp; MENTAL HEALTH: OUTPATIENT</b>							
Community Medicaid Expansion	FED	\$11,126,616	\$13,691,682	23.05%	\$13,691,682	0.00%	Funds community mental health; Medicaid services



Priority Area & Line Item	Fund Type	FY11	FY12	FY12 % Change	FY13	FY13 % Change	Description
<b>VOCATIONAL &amp; CAREER TECHNICAL EDUCATION</b>							
Career Technical Education Grants	FED/GRF	\$45,621,489 / \$2,180,282	\$48,466,864 / \$2,233,195	6.24% / 2.43%	\$48,466,864 / \$2,233,195	0.00% / 0.00%	Supports the development of academic, vocational, and technical skills of secondary and postsecondary students who enroll in vocational and technical programs
<b>JOB TRAINING</b>							
Federal Unemployment Programs	FED	\$197,122,072	\$188,680,096	-4.38%	\$186,723,415	-1.04%	Administers unemployment benefits and provides employment services
<b>VOCATIONAL REHABILITATION</b>							
Vocational Rehabilitation	FED	\$99,058,744	\$103,160,426	4.14%	\$103,150,102	-0.01%	Funds vocational rehabilitation services
<b>EDUCATOR WORKFORCE DEVELOPMENT</b>							
Improving Teacher Quality Grant	FED	\$2,723,206	\$3,200,000	17.51%	\$3,200,000	0.00%	Provides grants to universities to improve professional development projects for pre-kindergarten to twelfth grade teachers
<b>MEDICAL WORKFORCE DEVELOPMENT</b>							
Clinical Teaching (6 line items across 6 state colleges and universities)							
The Ohio State University	GRF	\$11,375,225	\$9,668,941	-15.00%	\$9,668,941	0.00%	Supports laboratory and clinical teaching components of the medical curriculum (e.g., physical therapy, occupational therapy, medicine, nursing) at each of Ohio's six public medical colleges
University of Cincinnati	GRF	\$9,355,968	\$7,952,573	-15.00%	\$6,198,600	0.00%	
University of Toledo	GRF	\$7,292,471	\$6,198,600	-15.00%	\$6,198,600	0.00%	
Wright State University	GRF	\$3,542,823	\$3,011,400	-15.00%	\$3,011,400	0.00%	
Ohio University	GRF	\$3,424,956	\$2,911,212	-15.00%	2,911,212	0.00%	
Northeast Ohio Medical University	GRF	\$3,522,563	\$2,994,178	-15.00%	\$2,994,178	0.00%	

<sup>1</sup> The fiscal year allocations provided in this table were obtained from each state department's respective Legislative Service Commission Greenbook (2012) retrieved from <http://www.lsc.state.oh.us>

## Investment Gaps in ASD Services and Supports

One wonders whether current investments in ASD services and supports are sufficient enough to support individuals with ASD across the lifespan. Future investment areas that address potential gaps and emergent needs may be identified via this fiscal analysis. As such, the current literature was reviewed to identify known gaps in the ASD service delivery system. The following gaps were identified, including the need for employment supports (Graetz et al., 2010), innovative technologies (e.g., laptops, Ipad, computer-training) (Bolte, Golan, Goodwin, & Zwaigenbaum, 2010); National Association of Special Education Teachers, 2006/2007), and professional development on autism spectrum disorders (Montes et al., 2009; Ruble et al., 2005; Stuart, Flis, & Rinaldi, 2006). These are priority gaps often described in relation to ASD services and supports. Once these gaps were determined, funds identified in the fiscal analysis that in turn could be used to address these gaps could be noted.

In the end, 8 budget line items provide support for assistive technology for individuals with disabilities and 6 line items reference vocational rehabilitation. The investment in these areas is small compared to, for example, early education and day care. Multiple line items support educator and medical professional development. However, only 1 line item specifically references professional development in the area of developmental disabilities and no line items reference medical professional development in the area of developmental disabilities. More detail related to funds available by each gap area is provided next.

### TECHNOLOGY

Technology usage among individuals with ASD is taking a prominent role in research and clinical practice related to individuals with ASD (Bolte et al., 2010). Technology can support individuals with ASD in a number of diverse ways (Bolte et al., 2010; Goodwin, 2008). For instance, computer-based training programs have the potential to enhance literacy, adaptive skills, social-communicative skills and emotional detection in individuals with ASD (Golan & Baron-Cohen, 2006; Golan et al., 2010). Further, the use of assistive technology may increase or improve expressive communication and attention skills (National Association of Special Education Teachers, 2006/2007). Eight budget line items provide support for Assistive Technology for individuals with disabilities. These funds are primarily housed in the Department of Developmental Disabilities (ODODD), Rehabilitation Services Commission, and Legal Rights Services. For example, through ODODD, County Board Waiver Match (SSR) and Family Support Services (GRF) dollars may be used for specialized medical, adaptive equipment, home modifications to accommodate the family member with a disability, and other services that meet individualized family needs. The Rehabilitation Services Commission allocates funds to Assistive Technology of Ohio which provides refurbished computers and computer equipment for people with disabilities. Additionally, the Legal Rights Service administers one line item, Assistive Technology (FED) that provides protection and advocacy to assist individuals with disabilities and their caregivers in the acquisition, utilization, or maintenance of assistive technology.

### EMPLOYMENT

Employment is a critical aspect of independent living for those with and without a disability. Research suggests an increasing number of individuals with ASD can work in a variety of community-based businesses and industries (Schaller & Yang, 2005; Boeltzig, Timmons, & Butterworth, 2008). Despite this, individuals with an autism spectrum disorder are often

unemployed or underemployed (Dew & Allen, 2007). In the current biennium budget, 6 line items reference vocational rehabilitation and these funds are primarily housed by the Rehabilitation Services Commission. Employment outcomes may be improved by targeting specific behaviors (e.g., social skills) common among individuals with ASD (SEDL, 2012). Additionally, systemic changes could be made including earlier contact with vocational counselors, training on working with individuals with ASD for vocational counselors, and a shift from short-term involvement to long-term support (SEDL, 2012). Also, more research is needed on the best practices to facilitate employment of individuals with ASD (SEDL, 2012).

## PROFESSIONAL DEVELOPMENT

Parents/caregivers of individuals with ASD often cite a gap in quality service providers (Montes et al. 2009; Ruble et al., 2005). Parents/caregivers of individuals with ASD are more likely to identify this as a concern compared to parents/caregivers of children with other disabilities (Montes et al., 2009). Eighteen line items across the Ohio Department of Education and the Ohio Board of Regents describe teacher and school administrator preparation and professional development. Several of these line items specifically reference supporting educators working in high need school districts such as school districts with a high number of low-income students and those with many students with behavioral problems such as truancy. Only one line item, Education of Exceptional Children (FED), describes the development of district and building leadership teams focused on the district-wide improvement of instructional practice and student performance, for all students, including those with disabilities. When families cannot afford other therapies and services for their child, they often rely on the school district to provide such needed services. Therefore, educator training and preparation in relation to autism spectrum disorders may be needed. Further, while the budget allocates funds to prepare medical professionals to work with special populations such as low-income and the aging population, preparation in relation to individuals with disabilities is not explicitly stated. This is concerning as families often go to their primary care physician when they initially suspect a developmental delay, so greater preparation in the area of ASD may be warranted.

In the end, funds were identified that might be used to support ASD related services, particularly in relation to these research-supported gaps. Efforts to fill gaps in employment supports, innovative technologies, and professional development through some of these mechanisms may be an important step for future ASD advocacy and policy work in Ohio.

## Summary

In summary, the fiscal analysis identified 3 line items that specifically reference ASD, 79 line items that support disability-related services and 142 line items that could be considered for leveraging to support ASD services. Several state departments (e.g., Ohio Department of Developmental Disabilities, Ohio Department of Education, Ohio Department of Job and Family Services) allocate funds in service of ASD pointing to the critical need for interagency collaboration in the delivery and coordination of services for individuals with ASD. The content analyses of program and service area themes allows for further insights into what ASD services and supports might be supported through each identified fund. Additionally, the fiscal analysis highlights 3 research supported gaps in services (i.e., technology, employment, and professional development) where current funding streams could be further leveraged. Certainly the identified funding streams might be leveraged through advocacy efforts to address the priority needs.

## PART II:

# Exploration of Parent / Caregiver Perceptions of Autism Spectrum Disorder Services in Ohio

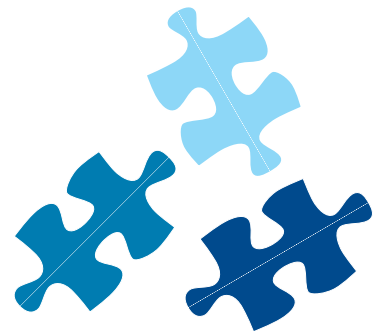
The second research component examined parent/caregiver perceptions of the ASD service delivery system, as well as their experiences with informal supports. The aim was to understand parent/caregiver experiences across the continuum of services (from getting a diagnosis of ASD to obtaining and maintaining services). We also interviewed ASD service providers and leaders in Ohio to distill further insights. The following key research questions guided the research:

- What types of interactions and experiences have parents/caregivers had in accessing supports for their children across system sectors?
- What are the gaps, barriers, and challenges to accessing services and supports?
- What are the funding streams parents/caregivers utilize to support services?
- In what ways do parents/caregivers of children with autism spectrum disorders connect with and support each other?
- In what ways might parents/caregivers of children with autism and low incidence disabilities support other parents/caregivers who are dealing with similar challenges?

## Research Procedures

Parent/caregiver participants were identified by OCALI staff and emailed a recruitment script or contacted by phone. Telephone interviews were then scheduled and conducted with parents/caregivers. Nineteen parents/caregivers of 24 children with ASD were interviewed. Of note, 5 parents/caregivers had 2 children with an ASD. A majority of the children of those interviewed were male (only 3 were female). This large difference is expected given the higher prevalence of ASD among males (CDC, 2012). Parents/caregivers lived in different regions of the state of Ohio. Table 6 provides a complete description the parent/caregiver and child characteristics.

Additionally, 9 service providers and leaders participated in a focus group or phone interview in order to provide further insights. A semi-structured interview guide with 5 questions was used to facilitate these discussions. Focus groups and phone interviews lasted approximately 60 minutes.



**Table 6. Parent / Caregiver (n=19) and Child (n=24) Characteristics**

Characteristic	#	%
<b>PARENT/CAREGIVER GENDER</b>		
Male	1	5%
Female	18	95%
<b>CHILD GENDER</b>		
Male	21	88%
Female	3	12%
<b>REGION</b>		
Central	3	16%
East	1	5%
West	1	5%
Southeast	4	21%
Southwest	3	16%
Northeast	4	21%
Northwest	3	16%
<b>RACE</b>		
Caucasian	12	63%
Unknown	6	32%
African American	1	5%
<b>AVERAGE CHILD AGE</b>	13.5	N/A

## Data Analysis

A content analysis of the interview and focus group transcripts was completed. Conceptual themes emerged through the data coding process, as recommended within qualitative research (Glaser & Strauss, 1967; Lincoln & Guba, 1985; Miles & Huberman, 1994). Three researchers independently analyzed the interview transcripts and met to review and discuss key themes and related concepts. Data from these interviews and the focus group were used to further inform the themes that emerged through the parent/caregiver interviews, thus serving as a form of validity check.

## Findings

Two broad themes emerged from the parent/caregiver interviews, including: 1) coping strategies and 2) service access and delivery. Each theme area was further broken down into more specific categories or sub-themes. In the area of coping strategies, relevant concepts included: life changes, emotional responses, social support, determination, advocacy and empowerment, staying positive and trying different things. In the area of service access and delivery, relevant concepts were organized according to whether parents/caregivers had positive or negative

experiences. For example, concepts related to parents/caregivers who had positive experiences when accessing and receiving services included: open and flexible communication, collaboration, responsive service providers, access to financial support, effective and high quality services, insider knowledge, parents/caregivers as providers/experts, and luck. Concepts related to parents/caregivers who had negative experiences when accessing and receiving services included: a delay in diagnosis, system disconnects, lack of information, lack of service provider knowledge, financial challenges, devaluation of parent/caregiver experience and expertise, and geographic inconsistencies. The themes are further described and elaborated with supporting direct quotes from parents/caregivers.

## 1. Coping Strategies

Parents/caregivers employed several different strategies to cope, including making life changes and sacrifices to accommodate the needs of their child with an ASD, displaying various emotional responses, accessing varying levels of social support (i.e. family, friends, connecting with other families/people affected by autism), displaying determination and persistence through various obstacles (i.e. when faced with unresponsive providers), engaging in advocacy and empowerment related to themselves, their children and other families (i.e. seeking out information on their own through research/internet; providing help and education to others), staying positive by maintaining hope and highlighting the unique strengths of their child, and trying different things when figuring out what works for their children and family.

### 1.1 COPING STRATEGIES: LIFE CHANGES

Parents/caregivers often reported making or contemplating major life changes to deal with issues created by having a child with autism (i.e. moving to a different state or county for better services; moving closer to family to strengthen the social support system; making a major job change, such as schedule changes or staying home to take care of their child; and leveraging financial assets to pay for interventions).

- » *“Everything kept pulling us to Columbus. My mom was here in Columbus. We decided to move back to Columbus and started a home program. X was diagnosed in November, sold house, quit job, started home program in February 2002.”*
- » *“I had tried to continue working after diagnosis, but none of the daycare centers had skills or training on how to handle him, so I was in constant turmoil. I placed him in one off and on to give me a break and I told them he was on a strict diet, they didn’t follow my instructions because they had a room full of typical kids. I just gave up and could not work, I quit my job, this all started from age 2-3.5. then did the home based preschool, the lady would come 2 hours 3 days a week and tried to do things she did with normal kids, but she didn’t have ABA training, it would have been helpful if she was skilled and knew how to deal with it. She had it in her mind this was just a typical kid.”*

### 1.2 COPING STRATEGIES: EMOTIONAL RESPONSES

Some parents/caregivers described daily challenges in emotional terms and having emotional reactions such as guilt, expressing that nobody understands them, feelings of desperation, not knowing where to go for help, family conflicts and marriage troubles, favoring their child with autism over other siblings, feeling like they have to wear multiple hats, and putting everything on the back burner.

- » *“The biggest strain early on when he was diagnosed and I moved here to Columbus. My husband couldn’t find a job and I quit my job so I moved out with X myself and I moved in with parents and lived with them for a year b/c my husband couldn’t find a job. Early on, when we were self paying we couldn’t afford a full team so I acted as the team leader and mom and dad. I would do different if I had to. To wear multiple hats was very stressful. Don’t be parent and therapist at same time; it’s too much you’re too emotionally involved. I don’t know if he sensed that, mommy guilt. I was so desperate for him to learn and do well, he’s such a people pleaser, he’s afraid to be wrong, is it because I was so crazy? It’s something I look back on and think this wasn’t the most ideal thing to do.”*
- » *“For our family it has really been a point where we have to sacrifice one child for the benefit of the other my daughter does not get to do the things she should nor do my husband or I get we haven’t had anniversary or birthdays for at least 6 years we haven’t participated in anything in life all hands on deck. In fact when we moved into this house we still had not gotten a full extent of what was in store as far as the level of need and we haven’t landscaped or put up curtains.”*

Parents/caregivers described their emotional responses to getting a diagnosis. Parents/caregivers illustrated receiving a diagnosis with initial feelings of loss, devastation, grieving, and mourning. Of note, parents/caregivers of recently diagnosed young adults described initial feelings of sadness and guilt for not knowing sooner; however also knowing at some level it was good to have a diagnosis in order to help put services in place. Young adults responded to the diagnosis with anger and frustration and didn’t think anything was wrong with them.

- » *“We finally know and the guilt of not knowing all of those years (e.g., Looking back: family gatherings) X would disappear and be in his room and I wouldn’t notice...It’s more noticeable now that we know and can see what is so different about him; Sad that I didn’t know when X was younger.”*

### 1.3 COPING STRATEGIES: SOCIAL SUPPORT

Parents/caregivers described access to or lack of social support such as family members, friends, other parents/caregivers of children with an ASD diagnosis, or support at work, as contributing to their abilities to cope and thrive. While parents/caregivers did have positive experiences with interactions with other parents/caregivers of children diagnosed with ASD, they also had some negative feelings and experiences about this type of support. Some parents/caregivers reported feeling that these groups could get overly negative/cynical. Sometimes parents/caregivers said they didn’t want their whole life and every social relationship to be about autism so they avoided doing too much with other parents/caregivers. Some parents/caregivers said that the parents/caregivers support was helpful early on, but that as they fell into a groove and learned more about autism and services, they found it less useful. Sometimes parents/caregivers described the natural cycle of a group forming, going through an active period and then a decrease in involvement.

- » *“I feel like you definitely click very quickly because no one else understands it, but I also don’t like where that seems to be your only common thread. Autism is a part of our life and I don’t need it in other aspects of my life.”*

- » *“Early on I was much more active and involved and [they] were very much a support to me. I’ve gotten so far from it I’ve forgotten. I don’t feel the need for the parent support thing... When X was diagnosed I knew no one who had a child with autism. Early on I needed that support because I didn’t have any interactions or contacts. Just to talk to another parent who knew what I was struggling with was a big deal.”*
- » *“Not involved in any support groups. I went to a couple autism society support groups, it was parents complaining about IEPs and teachers. I didn’t need more negativity. I needed support.”*
- » *“At the autism meetings I went to a few but they got too depressing and I stopped going...I would leave crying every time”*

#### 1.4 COPING STRATEGIES: DETERMINATION

Parents/caregivers often displayed extreme determination and persistence, whether surrounding obtaining a diagnosis, getting a referral for needed services, dealing with conflict or non-responsive systems or service providers, or addressing day to day struggles. This seemed to be a critical internal characteristic related to parents/caregivers getting the outcomes they wanted for their children.

- » *“At 9 months I took him to pediatrician for evaluation, the pediatrician wanted to wait; I was adamant and forced him to give me a referral to see how his development was progressing because at 9 months he wasn’t sitting up/rolling over.”*
- » *“I got really frustrated one time, I had (service coordinator) with me, X was self abusing by pinching, I was upset and took off all her clothes but underwear, I wrapped her in blanket and when the doctor came in I opened it and said do something, her whole body was covered in pinch marks and I wanted the doctor to see how bad she looked. My mom said he’s gonna think she’s a Munchausen kid. The doctor said okay, let’s get her an MRI, let’s get a psych, this was the third appointment for this and I was like I’m done, X was about 6 or 7 then.”*
- » *“It was difficult because neurologist had year long waiting list, so we got an appointment with someone else in that practice and he took a look at X and said let’s wait and see, I said no no because I wouldn’t be able to access anything, so went back to pediatrician, got new referral, started seeing new neurologist who ordered number of tests...we have to either fight for services or pay out of pocket.”*

#### 1.5 COPING STRATEGIES: ADVOCACY AND EMPOWERMENT

Parents/caregivers discussed several topics that relate to advocacy, self-education and empowerment as ways of coping with their child’s diagnosis and in responding to gaps or unmet needs. At times these methods involved reaching out to other parents/caregivers, at times parents/caregivers researched on their own to educate themselves which led to greater empowerment.

- » *“It’s a tough road but together we have power. We don’t have to wait. Parents need to get together, share, and get busy helping. We don’t have to wait for anyone’s head nod. There’s a lot we can do together, start organizations, tap into ones that have already been developed”*



- » *“Now I can go into a meeting, take charge, no such thing as a stupid question, I don’t even ask questions sometimes, I just go in and say what I want. I think about what’s important to my kid, don’t worry about stepping on toes.”*

Parents/caregivers also utilized the internet to find information, connect with other parents/caregivers who could relate, share their stories, and normalize their experiences. In some cases experiences with self-education through the internet was also seen as difficult.

- » *“Internet searches never had information under the words you looked at; Code words or need specific web addresses it’s more of a puzzle; You should be able to put in autism and find everything you need; One time I went to one web address and it took 10 or 12 sites to find what I was looking for.”*

## 1.6 COPING STRATEGIES: STAYING POSITIVE

Parents/caregivers frequently expressed a need and a struggle to stay positive. They described different strategies that helped them stay positive, such as rejecting the negativity of others, being less critical and more collaborative with service providers, and articulating the strengths of their child diagnosed with ASD.

- » *“A lot of us parents believe in recovery, I do, it’s not all doom and gloom, it’s hard work, but you can recover these kids.”*
- » *“My biggest thing is to never hate your kid, accept them for who they are, don’t be resentful of kids.”*
- » *“I’m trying to play to their strengths if you play on their strengths sometimes it helps them make up for difficulties or find a way around the difficulties.”*

## 1.7 COPING STRATEGIES: TRYING DIFFERENT THINGS

Parents/caregivers often discussed that they tried many different types of strategies in dealing with an ASD diagnosis and putting together a package of services that worked for their child. Parents/caregivers also often mentioned the need to try different things, remain flexible and attentive to when a change in the service plan is needed.

- » *“We tried everything, in home schooling, going to Cincinnati, going to school, in home school again, we tried school again and that’s now working.”*
- » *“At age 6 he plateaued, right before that we saw another neurologist, we wanted to change things up, he strongly encouraged us to access ABA, did another MRI. I was able to find by that point, they had started the school at Cleveland clinic, was able to find behaviorists, and able to start home ABA program, he had just turned 6, and he’s still on it now.”*
- » *“We went through a couple different family doctors before we found one that could take on the drug management responsibilities with respect to the medications he takes, willing to work with us and respond to us, especially if its medication at school, we need a doctor to respond quickly if we need an adjustment. If we’re not happy, we found someone else.”*

## 2. Service Access and Delivery

With respect to the theme identified as service access and delivery a number of related concepts were identified which are described below relevant to whether they were indicative of positive parent/caregiver experiences or negative experiences with service access and delivery. These concepts often cut across service access and delivery in multiple domains, for example there were commonalities in positive and negative experiences around service access and delivery across the medical system, the early education and school systems, community services and adult services.

Parents/caregivers also provided information about how they located services and the types of services they utilized. Parents/caregivers often located services through other parents/caregivers, online searches, children's hospitals, teachers, and county boards. In some cases, parents/caregivers had to find and locate a service for the doctor to then make a referral. Children received services in school, from county board, psychologists/psychiatrists, and therapists (speech, physical, occupation) and in some cases parents/caregivers themselves were providers. Perceptions of the effectiveness of therapies varied with applied behavioral analysis (ABA) and sensory techniques often described as effective. In some cases speech therapy was helpful but often times considered not sufficient or adequate. Children with an autism spectrum disorder have multiple, complex mental and physical needs. Common co-morbid conditions included hyperactivity, obsessive compulsive disorder (OCD), anxiety, and seizure disorder. As a result, they are often involved with multiple service providers. This sometimes resulted in differing medical opinions. Parents/caregivers highlighted communication and collaboration across service providers and with them as key to their satisfaction with the services.

Parents/caregivers reported using a variety of services some specifically focused on autism or special needs, including: ABA, autism clinics, special schools, in-home service providers (sometimes parents/caregivers served as the service provider developing their own ABA program, one parent was a nurse and her time was paid for by a waiver) behavioral services, consultants, speech therapy, occupational therapy, physical therapy, adult day programs, respite care, aids that provided social interaction with children, parallel play, alternative therapies (i.e. diets, cranial sacral, supplements; and some more general services such as food stamps, Medicaid. Although less frequently, other services were also mentioned such as sensory activities (e.g., brushing protocol, weighted vests), perceptual motor development, horse therapy, and adaptive equipment.

### 2.1 CHARACTERISTICS OF POSITIVE EXPERIENCES

Concepts generally related to parents/caregivers who had positive experiences when accessing and receiving services include:

- emotional support as well as concrete support such as writing letters to advocate for a needed service,
- open and flexible communication between parents/caregivers and providers (whether school, medical and community based),
- a collaborative experience between parents/caregivers and providers,
- collaboration and communication between the different service providers/systems serving the child, service providers who are responsive to parents/caregivers needs and inquiries,
- parents/caregivers who had more access to financial support through either personal, private or public funding (or a combination),

- effective and high quality services (also described as certain providers who went above and beyond to help them),
- parents/caregivers who had insider knowledge or knew someone in their life who had insider knowledge (i.e. one parent worked for school, one was a nurse, one was an audiologist and felt privy to more information in these roles),
- parents/caregivers who became their child's provider and provided expertise to others, and
- parents/caregivers who described being lucky (i.e. in the right place at the right time).

Even if providers did not have knowledge of ASD, if they were willing to learn and to help, they were appreciated and positively received by parents/caregivers. Parents/caregivers reported positive perceptions of settings (e.g., special school or community activity) that are designed for children with developmental delays that also employ individuals who "have a heart for kids like mine." Parents/caregivers appreciate providers who can make progress with their children.

- » *"I was lucky. I feel like it was divine intervention because I got the name of a social worker through Franklin county MRDD. I was trying to figure out the funding system, waiver, and I found the right people at the right time. I fell into things, rather than seek them out."*
- » *"Luckily with our early intervention in the county. I got a great transition specialist, Z, in the beginning when X was diagnosed, I got a person who wasn't very helpful, she just came to the house, kept me on track, nothing else. When X started school she stopped coming to the house and didn't send me on to another person. When X's behavior got worse, my girlfriend said call county DD, I said she's not DD, but I called and that's when I got Z, Z did everything for me, got me on right track on doctors, great suggestions, have you thought about checking in with doctor, checking out this type of therapy. Once I was bringing Z to meetings, like school meetings, Z would ask the best questions, now I can go without her . . . she taught me questions to ask, services to look for, gave me confidence to do these things on my own."*
- » *"When we moved up here our service coordinator said they're opening 50 slots, if you have active running full blown ABA, you get priority, and we were at that point, we were self paying. There were over 100 families in a room with yellow sticker, told they'd all get it, but only had 50 slots, our service coordinator was privy and on me to get everything done quickly to secure a slot. That's how it happened for us. I know families who worked at it for years, I don't have reason it didn't work for someone else. We had a great service coordinator. The consultant we hired said she knew a guy who's awesome. Z was my contact at MRDD and I requested a particular service coordinator and he was so Johnny on the spot had his finger on the pulse."*
- » *"Now that he has a medical card I've been able to do a little more thru Medicaid and private insurance through his mom, as far as specialists go, we take him to his pediatrician in this area, she's educating herself on autism thru me, another mom and research. . . But like his Ipad I knew this would be a benefit. We get the family resource funds thru county developmental disability board and I purchased his Ipad through that. That's been a great help, as far as other funding."*

Positive early education and school experiences generally were characterized by teachers/staff that were very responsive to parents/caregivers and their children (i.e. one preschool principal told a parent who didn't like her child's teacher to walk around the school and sit in on different classes until you find someone you like), made accommodations when needed (i.e. one teacher

created a special sensory quiet space the child could go to when she needed to get away from the group), were inclusive when needed, and were educated about how to work with children with special needs and autism (or became educated), also communication and collaboration at the education setting between parents/caregivers and teachers, teachers and other teachers/service providers, was open and healthy in positive experiences. One interesting point which is characterized by the following quotes, is that parents/caregivers usually had both positive and negative things to say about their experiences overall, even when describing only one experience.

- » *"I've had pretty positive reactions. My child's behavioral, but not in negative since, just quirky behaviors, they don't intrude on others usually. Day care was fine, they treated him as another kid, he tried to isolate himself, but they had a schedule and he followed it, so he did well. Same with center based... There have been occasions where staff, whether at camp, or at an event, where they've been hesitant to have him participate and we usually push through that and once he does, they realize it's not that big of a deal. There's not enough preschool/daycare with kids with autism, 4 hours a day, 2 days a week isn't enough, I understand there's a cost, but we haven't even scratched the surface of need."*
- » *"She went to special needs preschool for 2 yrs, they were responsive, but they didn't have staff to handle her behaviors, they only had one aid, and 6-8 kids and they couldn't just stop."*

In many cases parents/caregivers acted as the providers and experts. They often described their role as providing services to their children in a positive light and expressed feelings of empowerment and pride in doing so.

- » *"I grew up on horses and I worked with the OT and speech therapist and bought an old mare and I went home and did it with him and that's how we did it because the sessions were \$100 a session and insurance didn't cover that."*
- » *"Educate yourself, read as much as you can because you will be a doctor."*
- » *"I'm not an autism expert; I'm an expert on my nephew."*

Parents/caregivers described how technology was an asset for their children. In particular, technology facilitated skills and abilities and provided an outlet for their intelligence. Parents/caregivers also connected the use of technology to freedom and liberty for their children. However, getting payment or reimbursement for technology tools and appropriate integration of technology into the schools was lacking.

- » *"Couldn't get him to sit for 10 minutes before but now he sits for an hour with the Ipad."*
- » *"Technology is essential for his liberty I had to walk through fire to get his AAC."*

Overall parents/caregivers reported they felt that awareness and services available for autism have improved over time.

- » *"Getting initial diagnosis was very frustrating because of lack of support from the pediatrician. ... That's changed over the years, become much more proactive... I hope it's different for people today, so much more awareness. X's 12, we're going back several years and over last decade many changes."*

- » *“There were problems in the beginning because not a lot of doctors, pediatricians getting into it, but since that time, things have improved with new school at clinic and universities starting programs. It’s not as bad as it was, families can really access appropriate medical services, some doctors better than others. When we first started it was sparse...There’s a lot more than there was. I was there at the dawn of time and probably have a less tainted view because I’ve seen how far we’ve come. Others with more recent diagnosis maybe haven’t seen that. We’ve done a lot of work getting things going. From where we were, we are miles ahead.”*

## 2.2 CHARACTERISTICS OF NEGATIVE EXPERIENCES

Concepts related to parents/caregivers who had negative experiences when accessing and receiving services include:

- parents/caregivers that experienced delays in diagnosis from a professional despite their own feelings that something was off,
- system disconnects (i.e. between diagnosis and referral, between multiple providers that didn’t communicate with each other),
- lack of access to information,
- lack of service provider knowledge,
- parents/caregivers who had financial challenges or experienced problems such as long waiting lists for services,
- parents/caregivers who felt their experience and expertise was devalued by providers, and geographic inconsistencies.

It is important to note that while the overall pattern of positive versus negative experiences varied by family, all parents/caregivers had both positive and negative experiences in relation to service access and delivery.

Negative experiences in school were characterized by teachers, administrators or staff not knowing how to handle the child, using scare tactics, avoidance (sending the child home), and inappropriate punishments.

- » *“School therapists have many kids, can’t give enough attention, so I bowed out of services through school, except for speech, she was on the same page and would consult with our outside people and we took him out at age 7. I felt bad because I hadn’t done it sooner, it boiled down to, I had to fight to get him a personal aid and when they gave us one, she wasn’t up to par, she wouldn’t do what she was supposed to do, they created an IEP, but wouldn’t follow, I got her to attend speech therapy, so she could implement in classroom, but she wouldn’t do it. He was getting lost, wandering, they were calling me every day to come get my child, why am I keeping him here, they don’t want him, I wasn’t the only family there with that problem.”*
- » *“He was held down in restraints for a full day and they didn’t let us know they just said, “he had a rough day but we got through it.” We got access to records by asking to look at his file, went in and spent a day copying, we had no idea that restraints were happening with 3 of them needed to hold him down on floor for 20 minutes, there was 1 incident, it was 4 consecutive restraints, no wonder he has anxiety! School felt completely justified. There is a*

*big lack of appreciation for neurology of these children, assuming they are making conscious decisions, this was at an autism school too.”*

- » *“Teachers need training on autism and how to deal with it because they don’t know how. They want to pigeon hole kids and use methods they’ve been using with everyone else but each child is different in terms of what they need.”*

Parents/caregivers also struggled with getting the medical community to hear them out and respond early on. Parents/caregivers often knew or suspected something was wrong very early and had to be insistent on getting a diagnosis. Parents/caregivers recounted long delays, ranging from several months to years between having concerns and actually getting a referral, screening, and diagnosis performed. In many cases the delay was attributed to the medical professional minimizing the parents’/caregivers’ concern and normalizing the developmental delay(s). Along these lines a perception seems to exist among both parents/caregivers and professionals that boys develop at a slower rate than girls do. Often times this was used as an excuse or an explanation for a child’s developmental delay. Other explanations for the delay included waiting lists to get initial testing and lack of certainty on where the child was on the spectrum. The delay in diagnosis was concerning as parents/caregivers recognized the importance of early intervention in improving outcomes for their children.

- » *“It was exacerbating between 96-97 we saw 5 different people...none of them would give us a diagnosis that included going to Rainbow Babies to see the big guru of diagnosing kids with autism my son saw him at just about 3 years of age and literally I wanted to choke the man...he it was...he was very brash and rubbed me the wrong way to begin with but to say it doesn’t matter what his diagnosis is he is still a problem. If he is doing this in 9 months I’ll see about a diagnosis. I didn’t think we had 9 months. After that it was a roller coaster some people would say it’s a phase, some say MR for the rest of his life and should be in a institution and I went and found that SOB and give him a piece of my mind. But the idea is nobody wanted to give us a diagnosis at that time. I finally got a psychologist to run all of the different behavior test shortly after my son turned 3 we found a guy in Toledo who would do that. I can’t give you an autism (5 instead of 6 symptoms) but I suggest a diagnosis of PDD NOS and that will suffice for treatments and whatever else you need and within a couple of months of that June after he turned 3 he started an ABA program with one of the ABA places.”*
- » *“I didn’t suspect autism, my sister told me to get him checked out. I told pediatrician, and he kept blowing us off, at age 2, I went in and said, I need you to send me somewhere, he’s not developing, losing skills.”*
- » *“And the first pediatrician that wouldn’t refer, I felt like he was dismissing me, I was telling him he was losing his speech, severely sick with stomach issues, he kept telling me it’s too soon to tell, give it some time. I trusted him, against my better judgment, things just kept getting worse, I said I can’t do it anymore one day, he refused me, so I went to his supervisor, and he agreed with me and immediately scheduled help.”*
- » *“I was concerned about her speech at 2, and they said she’s just delayed at her normal checkups, I told them she’s not talking, and I was hoping it was just delay so I took their word. But I could have gotten services sooner. Then the pediatrician got upset at 3.5 when he had to do the referral, but he did it.”*

Part of the diagnosis process included having multiple evaluations across medical, psychological, educational, and occupational domains. The evaluations were sometimes described as having a “cookie cutter approach” and were in some situations not followed up with service referrals. The diagnosis experience was similar for parents/caregivers who identified concerns in their children at a young age. However, parents/caregivers of young adults diagnosed with Asperger’s disorder had a unique experience. In particular, parents/caregivers reported difficulty in completing assessment forms that asked them to recall how their child was during their toddler and preschool years.

» *“We filled out a bunch of forms about how he was when he was under 5 years...It was hard to answer the questions because he was 23 at the time.”*

Parents/caregivers identified having a diagnosis as key to qualifying for services and getting services in place. In many cases, a diagnosis then allowed access to services with various agencies such as county boards. However, in many cases, parents/caregivers described feeling abandoned or left with little direction. Parents/caregivers also reported not being given all of the information that could have been useful to them about accessing and paying for available resources.

» *“You have the grief and then you are abandoned by the community and sometimes they get dangled in front of you and then take them away; it’s like trying to run through a maze blind folded.”*

» *“Given a diagnosis and then sent out and you are back to the library again to do research...It’s more of a puzzle than what your children are going through; It was never cut and dry it was you have to make this call to find out another call, and on and on. Throw you a bone knowing it will go to a dead end. Since the diagnosis, I have been down many roads and many dead ends. It’s been a nightmare it’s still a nightmare it’s actually gotten worse.”*

» *“The ABA, I was not told, I wish that, the one thing I’d like to see is that doctors in our state are mandated to give parents better resources when they leave doctors office, create a “no parent left behind” policy, we’re not given information on therapies just a diagnosis. With my son we didn’t have it, but with my grandson, no one told me Ohio had a scholarship program. So I did my own ABA after researching.”*

» *“...Diagnostic team does a thorough job but then they don’t give specific strategies and things to go away with. You drive an hour to get there and then they don’t give you anything. The distance was hard with X. They have some things for parents and kids but they are all in Columbus and if you live an hour a way you can’t drive there a couple of times a week to do these things. We did 6 hours of testing and then came back 3 times, just for them to give us a diagnosis. We went there for behaviors strategies and we left with nothing, they didn’t give us anything.”*

Parents/caregivers frequently reported perceptions that services are out there if you can afford them. They often commented that it is not a problem finding people who want to help, but paying for services is a challenge. Specifically, parents/caregivers noted a gap for the middle class and changes overtime in insurance coverage. Parents/caregivers reported paying for services in a variety of ways including through county funding, waivers, private insurance, Medicaid, Medicaid waivers, Bureau for Children with Medical Handicaps (BCMh), hospitals, out of pocket, and grants. Sometimes it was enough, and sometimes they still couldn’t afford what they wanted.

Therapies parents/caregivers could not afford and that are often not covered with insurance included private and/or special schools, private therapies and providers, horse therapy, co-pays, extracurricular activities, summer camps, applied behavior analysis, sensory equipment, and communication devices. Therapies not covered by Medicaid included an Ipad, out of state specialists, ABA, and sensory equipment. Parents/caregivers connected the lack of funding for needed services to inadequate services and poorer child outcomes. Parents/caregivers often tried locating services with a sliding scale fee. Parents/caregivers described how only a certain number of sessions were covered for therapies, so they had to be very picky as far as what service and provider they selected.

- » *“Well, a lot of it was if you were working and if you needed financial aid because you were the working poor if you made too much money you didn’t get the services even if you were a few dollars over the limit. My husband and I have always tried to work and pay our way and we get punished for that and it ain’t cheap to go to the doctor.”*
- » *“My younger son could have gotten more strides but I’m not a wealthy man. We’re not talking cheap here and we couldn’t get it handled for my youngest. He would have done better if he had early on OT sessions that my oldest got... Would have made better strides in life had he gotten OT services. My oldest son received more OT services than my youngest son and he manages his issues much better.”*

Some parents/caregivers also described situations that transcended affordability issues and discussed services that weren’t available at all in their areas.

- » *“There isn’t anything in our area, no play groups for special needs kids, we can’t just put our child in t-ball, soccer. I’ve tried to get people in the community to start something, hard to get people to do that. My child has never got to experience, he doesn’t get to socialize with other children, our support group will get kids together with tumbling, but not much.”*

Parents/caregivers often mentioned issues about services not being consistent from county to county, state to state, or between urban and rural environments. This often provoked moves or long travel times to access services.

- » *“It depends on geography, some parents have found insurance will pay for a lot, one family whose whole ABA, preschool & toddler program was paid for by insurance, and then there’s others for whatever reason haven’t been able to access too much of anything, another friend whose son has significant behaviors and he’s getting big and her support admin gave her a guilt trip about applying for waiver and said its only for most intense needs, and I’m thinking if he’s beating you up and you can’t control him. Some counties have better services and school districts too.”*
- » *“The county I’m working with there’s nothing in this area, no resources, no services, what can we do as a whole state to come together and help this area get things. Families in rural areas can’t get to larger cities and they’re being left in the dark. You can see in maps where there are support groups, and where there aren’t, there are some counties with nothing, when you plug in resources per county, you see them in Columbus, Dayton, Toledo and Cincinnati, nowhere else.”*



- » *“There’s no doctor here, even our therapy department, they’re not trained to work on sensory issues, we have to travel at least an hour to get services...My goal is to open an autism center here because we have to travel so much. I would love to see all the specialists these kids need in one building.”*

Parents/caregivers reported being able to get access to some much needed services through waivers, but also were told they couldn’t get access to certain services through waivers (i.e. startup schools), or needed more services than the waiver allowed for, or they reported they weren’t told they could use a waiver for things and later found out they could. Some parents/caregivers said they were able to get waivers right away; some had to wait for months or years or knew other parents/caregivers who had to wait.

- » *“Probably with me, when we got on the waiver. I’m a single parent. It just gives me 20 hrs a month of respite, but it doesn’t go very far. I don’t have grandparents to step in and give me a break. I’m with him constantly. It’s hard for the families that don’t have help.”*
- » *“Took a long time to get waiver, they cut all the waiver days down to 90, that will be difficult because X is used to going every weekend. That won’t work, so we’re trying to figure out ways to do that. So even the waiver, we have the best possible, but there’s still limitations. I can get some transportation needs, but still limitations, the waiver can’t take care of everything for everybody. I have money to have an aid at home and X doesn’t allow anybody to come in, the aids that come in are nice girls, but they’re not used to dealing with her behaviors.”*
- » *“At a loss for how to utilize the benefits they say we qualify for. Knew there were supports I could access but didn’t know how. Not exercising full benefit. It’s one of those things we can’t seem to use the tools.”*
- » *“On wait lists to get different types of living waivers IO. Waiting lists don’t move much. Lost 2 years thinking X was on the waiting list when he wasn’t.”*
- » *“So we do need waiver services for nursing and our support administrator has been trying to work with us on that, it’s been long and difficult. We went through 6 different support administrators. We’d get one, tell our story and she’d quit or get fired, then 6 months to get new one, that’s why he doesn’t have waiver services.”*
- » *“We’re waiting on a waiver that would help for provider, someone to take her places when I work. I’ve only been waiting 4 yrs, that’s not very long, usually it takes a lot longer.”*

Parents/caregivers reported difficulties in getting services geared towards individuals with autism and special needs at times, but also difficulties in finding every day services such as primary care physicians, barbers, dentists, etc. that knew how to work with individuals with autism, or had some awareness about this population.

- » *“Once our eye doctor told us not to come back, dentist same thing. There were problems in beginning because not a lot of doctors, pediatricians getting into it, but since that time, things have improved with new school at clinic and universities starting programs. It’s not as bad as it was, families can really access appropriate medical services, some doctors better than other. When we first started it was sparse.”*

Parents/caregivers often reported feeling blamed for their child's delays, dismissed, and not considered an expert in relation to their child's needs. This emerged across service domains including medical, educational, and community settings. Parents/caregivers reported perceptions of feeling like a bad parent and feeling blame from community members. Parents/caregivers express a desire to be listened to and collaborated/partnered with in determining and providing services to their children. Parents/caregivers believe this collaboration would be beneficial for their child's progress. Parents/caregivers also desire to be respected and have their questions answered. Parents/caregivers need their experiences with their children to be validated as real. If parents'/caregivers experiences are not validated, they may feel like a failure. For example, one parent discussed noticing improvement in her child with a gluten free diet; however the benefit of a gluten free diet was dismissed by the child's physician. Parents/caregivers often feel alienated by language that they don't understand, for example, the school system language.

- » *"They make the family feel as if it is their fault the child is like this you are a bad parent, you aren't teaching them manners...that's not it."*
- » *"I had a high school education and they talked like college level and I didn't know what they were talking about instead of including me as a partner. You know what I mean sometimes the parents feel alienated. Well it's like a parent with a second language how they don't understand the school system. A lot of times with autism if the teachers would coordinate with the parent and both do the same thing the child would progress more."*

Parents/caregivers frequently pointed to a knowledge of (and lack of knowledge of) and awareness of ASD and related symptoms across service domains. They noted difficulties in finding physicians and teachers who understand what autism is and how to work with children who have autism. In some cases, parents/caregivers described a lack of understanding or a lack of willingness to understand the biochemistry of autism. A related issue was a lack of specialty services for children diagnosed with an ASD. In addition to knowledge and awareness, the quality of services is of concern to parents/caregivers. For example, parents/caregivers questioned the quality of the employment transitions and support services and opportunities.

- » *"I set up an appointment with my doctor and he said to find a place; I had to find these places because the doctors don't know about them parents have to find them; Doctor offered to write a script for X to get tested if I found a place for him to be tested."*
- » *"Um well, the people we have seen here don't understand the biochemistry of autism they think therapy is the only path and people like me are in denial but I see progress, I document, I live in and breathe so those opinions don't have weight with me."*

Parents/caregivers reported a need for adaptations for children with ASD across settings, medical, educational, occupational. Routine medical exams such as dental and eye exams are often traumatic for children with an ASD. Parents/caregivers suggest providers allow extra time for appointments with children with an ASD and patience. Similarly, children with ASD often have sensory issues. For example, the school environment is not sensory friendly with bells and crowded hallways. Such experiences of overstimulation may lead the child to have a sensory meltdown and act out. Sensory issues may also inhibit learning. Along the lines of accommodations, parents/caregivers reported trying multiple educational settings for their children including regular classroom, disability classroom, and special schools trying to find the most appropriate learning environment.

It appears children with ASD are unique. For example, a child with higher functioning autism may be placed in the general education classroom but teachers then don't know how to handle him. Parents/caregivers like for their children to be in the inclusive classroom as they can learn a lot from observing other students. Also, when a child is improving, the school believes the child does not need additional learning supports and that they are not autistic anymore.

» *“He will put his head down when you are reading to him so he can shield his eyes and hear the story.”*

Parents/caregivers described experiences of discrimination and disparities related to insurance coverage, service availability, and employment opportunities. Parents/caregivers reported insurance companies see autism or autism related diagnosis and deny coverage; however they will pay for services if the bill code does not say autism. Parents/caregivers view insurance benefits as an issue of equality for their children. Also, parents/caregivers observed if services got expensive, insurance premiums charged too much. In some cases parents/caregivers avoided diagnosis because they knew their insurance company would not cover their medical needs.

» *“Some states are requiring services be covered but Ohio is not a place that bill keeps getting out but that's completely an area of heartbreak for us.”*

» *“Hard because the doctors they don't take insurance, well they do take insurance but insurance doesn't pay for the services. They get around that now by using codes for the medical issues, so instead of coding as autism, they code for medical things like chronic constipation, diarrhea, or seizures.”*

There are also perceived health, region, age, and functioning disparities in relation to autism services and supports

» *“Where I worked I did research on health disparities for autism and looked up that information and somehow my name got connected with that area. I would get phone calls from low income and inner city people who couldn't get services because of insurance and money and that was a really big issue. I didn't experience this but it was an issue for lots of other people...“All the services are in the nice cozy suburbs, there's nothing for inner city people of Cleveland.”*

» *“They will help the younger ones. They say we only help 18 and younger.”*

Discrimination in occupational services lack of acceptance, perception not capable based on first impressions, terminated from jobs, etc.

» *“As he got older, couldn't hold his jobs; terminated from job due to an interaction with another employee. They just moved him around and didn't give him a chance.”*

» *“They did an evaluation where they do motor activities and the guy who evaluated her...X enjoyed doing the evaluation and felt she did a good job but her speed was like at a 0% so this guy said she is not competitively employable and that was it. She had a transition coordinator who was really behind her and helped her in lot of different ways and helped her get into an intern program at north east career center in Columbus schools and the internship program was essentially learning computer programs and data processing and then working in different*

*offices and the teacher didn't want to accept her and felt she was severely handicapped and I said well after 6 weeks if it isn't a good fit by October she said she's doing fine and she got the award for the most outstanding person. She's always proven herself that's why advocating her has been worth doing. She uses the services ...she gives a poor first impression and people think she's not capable of doing things."*

## Validity Check: Results from Focus Group and Interviews with Service Providers and Leaders

Obtaining data from multiple informants strengthens the rigor of qualitative studies such as this one (Padgett, 1998). Therefore, the focus group and service provider interviews were used as a validity check for the parent/caregiver interview findings. Overall, the focus group and service provider interview participants validated the findings from the parent/caregiver interviews. They identified several gaps in the ASD service delivery system such as geographic variation in the availability of services, access to medical evaluation and diagnosis, employment options and supports (e.g., transportation), social skills and emotional regulation, and long-term supports (e.g., housing). The participants recognized that some individuals with ASD are well situated to receive services "while others are lucky if they even get a little time for speech, for instance." Along these lines, one provider elucidated on the geographic variation in funding due to levies and the difficulty in paying for services:

*"The levies have made the services county specific. So if I live in Franklin, the wealthiest, I have a better chance of accessing services than in Morrow County that hasn't passed a levy in 15 years. So if I live in Morrow County, I'm going to get education service but not much beyond. If I live in Franklin County I will get early intervention to aging services. You won't find that in other states in other states, where there isn't consistency it's because of distance and proximity. Where I live is who pays for the service. Even if I have the means to travel there is no means to pay unless I'm also poor but if I'm middle class my insurance isn't going to cover it and local tax dollars aren't."*

The above quote illustrates not only the regional disparities in autism related services but also the gap in funding supports for middle class families who rely on private health insurance. Additionally, as noted by parents/caregivers, the participants also confirmed the fragmentation in how services are funded and provided as illustrated in the following quote:

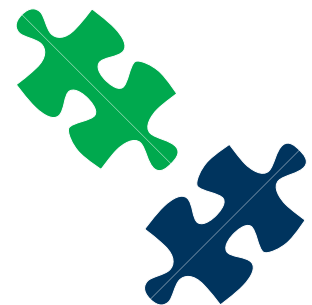
*"Education doesn't talk to DD who doesn't talk to ODJFS who doesn't talk to ODH because we are funded so different each system keeps its own self going and there isn't a whole lot of time and energy to talk to anyone. If it was a team approach, we might be able to help people but systems aren't coordinated. That's a huge hole."*

The leaders and service providers also validated parents'/caregivers' experiences of confusion in relation to how services are paid for in Ohio. One participant stated, "Parents don't know who will pay for what; if we as a state looked at an integrative approach for funding it would help services are too fragmented and siloed." Also of note, parents/caregivers of young adults described issues related to securing employment (e.g., distance from available jobs). The service

providers and leaders echoed some of these issues describing barriers to employment such as rurality, distance from viable employment options, and not having a valid driver's license. Service providers and leaders emphasized the importance of adult supports including transportation, housing, and employment, all of which are concerns on the horizon for parents/caregivers of young children with ASD. To sum up, discussions with service providers and key leaders in the area of ASD services confirmed many of the concerns expressed by parents/caregivers.

## Summary

In summary, the parent/caregiver interview, as well as the focus group and interviews with service providers and leaders, illustrate the experiences of parents/caregivers and individuals with ASD especially as they navigate the ASD service delivery system. Parents/caregivers cope with the diagnosis and the process of obtaining services using a number of strategies (e.g., determination, focusing on strengths) and report both positive and negative experiences in accessing services. These findings were validated through the focus group and interviews with service providers and leaders. Overall, participants perceived that the services and supports for ASD have improved overtime. The findings from this component, however, provide key insights into how the current system might be improved, particularly by addressing the perceived gaps and barriers to services identified here.



## PART III:

# Synthesizing the Results: Discussion and Implications for Practice, Policy, & Research

## Discussion

The prevalence of ASD has risen over the past several decades (CDC, 2012). As a result, service providers are confronted with individuals and families seeking services for ASD. At the same time, public revenues for ASD related services are decreasing, thus challenging states to meet the growing demand for publicly funded services with fewer dollars (Mauch et al., 2011). This study aimed to identify federal and state funding streams that are available or may be used to support ASD in Ohio and to explore parent/caregiver experiences with the ASD service delivery system and informal supports. Overall, the findings offer insights into how the ASD related services in Ohio might be enhanced, as well as identify what types of resources might be leveraged in order to achieve a strengthened system.

More specifically, the fiscal analysis identified 3 line items that reference ASD, 79 line items that support individuals with disabilities, and 142 line items that could be further explored for their leverage potential to support autism spectrum disorders. These line items are spread across a number of different state departments clearly indicating the need for cross agency collaboration in program development and grant writing.

Seventy-four service theme areas emerged from the content analysis. The theme areas with the largest number of line items included: parent/family support, home and community based supports, job transition and workforce development and unemployment, nutrition, child and adult protective services, collaboration, health (treatment and disease and injury prevention), college awareness and access, and early intervention and child care. Technology, employment, and professional development represent priority gaps often described in relation to ASD services and supports. The fiscal analysis identified potential funding streams that could be used to address these gaps including 8 budget line items for assistive technology, 6 line items for vocational rehabilitation, and multiple line items support educator and medical professional development.

Two key theme areas emerged from the parent/caregiver interviews, including: 1) coping and 2) service access and delivery. Parents/caregivers cope using a variety of strategies such as making life changes and sacrifices, accessing varying levels of social support, and displaying ongoing determination and persistence when faced with various obstacles (i.e., unresponsive providers). Overall, parents/caregivers recognized that the services and supports for ASD have improved overtime and noted both positive and negative experiences with service access and delivery. Positive experiences were illustrated with open and flexible communication with service providers, providers who were responsive, willing to learn, and valued parents/caregivers opinions, when parents/caregivers reported that either they or someone they knew had insider

knowledge, and when parents/caregivers were able to piece together various funding sources to obtain needed services for their child with an ASD diagnosis. Negative experiences were typified with delays in receiving an initial diagnosis, non-responsive and/or unqualified service providers, system disconnects (i.e. between initial diagnosis, referrals to other types of services and information about how to obtain financial assistance for services) and the lack of needed services and further lack of financial means to obtain needed services. Gaps in ASD services included those for young adults (e.g., independent living planning and employment training and support), extended school day, social skills and emotional regulation, quality service providers/information, sensory equipment, and community awareness and education.

## Synthesis of Findings

A few comparisons and contrasts between the fiscal analysis and parent/caregiver interview findings also help further inform the research. First, the parent/caregiver interviews suggest that some of the ASD-specific funding streams may not be beneficial for all families of children with ASD. For instance, while the Help Me Grow line item funds an early identification program, parent/caregivers often reported delays in receiving a diagnosis. This is problematic as getting an early start with intervention is important for successful outcomes. Also, the Autism Scholarship is a main ASD related line item. However, sometimes the parents/caregivers interviewed do not access that funding rather they try working with their local public school and using special education services. One explanation given by parents/caregivers for this decision is that there are often costs above the allocated \$20,000 scholarship that are beyond what parents/caregivers can afford. No other explanations were provided. Therefore, future research may investigate parents'/caregivers' perceptions of the Autism Scholarship Program, specifically exploring reasons they utilize or don't utilize the program.

Secondly, Medicaid waivers are a significant disability related line item and frequently came up in the parent/caregiver interviews. When parents/caregivers are not eligible for Medicaid or do not receive a Medicaid waiver, they pay for services using private insurance and/or out of pocket. At times parents/caregivers reported having to suspend, forego, or delay the utilization of services which they believed to be beneficial to their child. This often creates significant financial strain. Medicaid waiver funding helps parents/caregivers to alleviate the cost of home and community-based services. Medicaid waivers are helpful but also present a source of stress as parents/caregivers experience waiting lists and lack of clarity on how to use the funds.

Further, dollars are available to support certain gaps noted by parents/caregivers. For example, although the funding streams are not specifically dedicated to professional development around ASD, dollars are available to support educator and medical professional development. Parents/caregivers cited concern about the quality and knowledge of service providers across domains. Also, parents/caregivers cited examples of discrimination across settings and the presence of regional disparities with services. The Legal Rights Service's largest funding stream is dedicated to the provision of protection and advocacy for those with developmental disabilities.

## Action Steps and Related Recommendations

The findings from the 2 components of this study offer important implications to inform and enhance future ASD practice, policy, and research. Together these findings point to several action steps and priorities. The fiscal analysis calls for:

- Continue the promotion of cross-agency collaboration in program development, administration, and grant writing at the state-level.
- Consider funding integration particularly in relation to the 3 primary ASD line items and the inclusion of individuals with ASD in disability-related (e.g., Vocational Rehabilitation) and general population funding streams (e.g., Unemployment).
- The exploration of identified funding streams that could be leveraged to support ASD related services across the continuum services and lifespan, particularly in areas where there are gaps such as technology, employment, and professional development. Future consideration of ways to maximize the disability-specific line items and those for the broader population for ASD services and supports. This could be achieved by contacting the controlling agency for each line item to learn how the dollars are allocated to providers. This work could be accomplished through the Interagency Work Group on Autism.
- Support advocacy efforts that leverage funding streams and policy structures in order to improve ASD services and eliminate disparities [e.g., health insurance coverage, regional funding and service disparities (e.g., county disparities in eligibility, funding, and service capacity)] in ASD service delivery in Ohio.

Parents/caregivers experiences document action steps related to:

- The need for clear, concise, and coordinated communication to parents/caregivers about how to access services and what types of financial supports are available to support individuals with ASD throughout the life span.
- The improvement of collaboration and communication among parents/caregivers, service providers, and others involved in supporting individuals on the spectrum. To facilitate continuity, providers should communicate knowledge of needs and strategies/services that worked in one stage that should be transitioned to the next.
- Continue to develop and enhance professional development and pre-service training on ASD for educators, medical professionals, and others who work with individuals on the spectrum, particularly in relation to increasing awareness of the early signs of ASD.
- Additional inquiry into the design and implementation of parent/caregiver support groups and other informal support activities so that improvements in these social supports may be made.
- Further research with ASD service providers to obtain their perspectives on the current service delivery system in relation to gaps, barriers, and suggestions for improvement.



## Study Limitations

While efforts were made to ensure threats to validity and reliability were reduced, all research designs face limitations. The fiscal analysis findings should be interpreted with consideration to the study limitations. We were over-inclusive when identifying funding streams that could potentially be used to support ASD. For example, if a funding stream earmarked dollars for programs and services related to individuals with disabilities in addition to other general population related earmarks, the line item was included; even though all of the dollars allocated for the line item are not designated for youth programs or services. While over inclusivity is beneficial, in some cases this resulted in higher dollar amounts than what may be the reality. Additionally, with the line items identified for leveraging, limitations in the use of these line items for ASD are possible. For example, some line items include earmarks and eligibility requirements (e.g., income guidelines) that specify how and on whom dollars may be spent. Despite this limitation, the fiscal analysis provides a starting place for the exploration of potential funding streams to leverage for ASD services and supports

The parent/caregiver interview findings also have limitations. The results are based on interviews with 19 parents/caregivers. While attempts were made to have a regionally representative sample, the race and ethnicity was unknown for over a third of the study sample. Also, the socioeconomic statuses of the parents/caregivers were unknown. Therefore, the generalizability of the findings may be limited. Also, despite best efforts, recruiting ASD service providers and leaders was challenging. Therefore, their full perspective on the ASD service delivery system is missing from this analysis.

In spite of these limitations, several strategies were used throughout to minimize these limitations. For instance, we had two researchers code each of the 390 line items separately to add reliability to the fiscal analysis findings. Additionally, we used the focus group and interviews with service providers and leaders as a validity check for the parent/caregiver interview results.

## Conclusion

In conclusion, the study findings provide a picture of a current service delivery system and funding streams for ASD. Based on the parent/caregiver interview responses, the availability of services has improved overtime providing an optimistic outlook on the possibility for continued improvements. This two-part study provides implications on what the improvements might include, such as leveraging funding streams in support of ASD in relation to areas of need (e.g., employment supports) and enhancing the pre-service and in-service training opportunities for service providers who work with the ASD population. The action steps outlined provide potential next steps in enhancing the service delivery systems for individuals and families impacted by ASD.

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# Appendix A

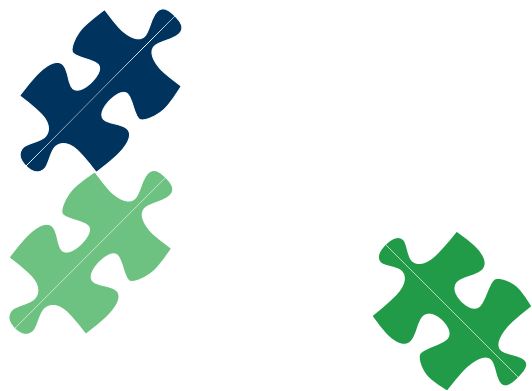


**Table 7. Theme Areas and Number of Related Line Items**

Theme Area	Number of Line Items
Prenatal and Maternal Health	3
Early Intervention & Child Care	20
Special Education	14
Academic Achievement	18
Science, Technology, Engineering	6
Afterschool	2
Tutoring & Mentoring	3
School Health	2
School Transportation	1
School Choice	1
Distance Learning	3
Curriculum Managing & Academic Content	3
Student Assessment	2
School Evaluation, Improvement, & Accountability	15
Educator & Principal Quality: Preparation, Professional Development & Evaluation	18
Dropout Prevention, Retention, & Graduation	4
Postsecondary Counseling & Planning	8
Classroom & Career Collaborations	3
College Awareness & Access	21
Postsecondary Remediation & Retention	5
Vocational & Career Technical Education	13
Job training & Workforce Development, Investment, & Unemployment	26
Vocational Rehabilitation	6
GED & Adult Education	10
Agricultural Industries, Economic Development, Lake & Coastal Resources	6
Healthcare Workforce Development & Research	13
Parent/Family Support & Assistance	37
Cash Assistance & Social Services	16
Child Support	6

Theme Area	Number of Line Items
Child Welfare & Adult Protective Services	24
Residential Facilities	18
Home and Community-Based Services	35
Case Management	9
Nutrition	25
Assistive Technology	8
Advocacy	16
Health: Treatment	23
Health: Education, Awareness, & Referrals	17
Health: Disease & Injury Prevention	21
Immunizations	5
Oral Health	3
Hearing & Vision Services	2
Rehabilitative Services for Children with Special Needs	1
Environmental Health & Emergency Preparedness	7
Behavioral & Mental Health: Outpatient	18
Behavioral & Mental Health: Inpatient	12
Mental Health Promotion	3
Substance Abuse and Gambling Addiction Treatment & Prevention	19
Mental Health Care Funding: Medicaid & Other Funding Sources	9
Health Care Funding: Medicaid	18
Health Care Funding: Medicaid Waiver	4
Health Care Funding: Children with Medical Handicaps & Other Funds	7
Health Care Funding: Medicare	2
Forensic Psychiatry & Evaluations	1
Higher Education: Research Support	8
Higher Education: Information Sharing, Computing, & Library Resources	5
Juvenile Delinquency Prevention, Diversion, Intervention, & Treatment	7
Inmate Payment for Work, Education, & Recreation Funds	3
Prisoner Pre-Release Programs & Release Payments	2
Community Support & Monitoring for Released Offenders	3
Sentencing Alternatives	4
Victim Services	2
Collaboration	24

Theme Area	Number of Line Items
Operations	
Corrections	23
Drug and Alcohol	2
Mental Health	13
Developmental Disabilities	5
School	24
Health	7
Job and Family Services	23
Legal Rights	2
Rehabilitation	2
Higher Education	10
Youth Services	5





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