

Arts & Autism in Ohio Research Initiative

Phase 1

Findings and Recommendations 2013

A project of



Prepared by



77 S. High Street, 2nd Floor
Columbus, OH 43215
614.241.5325
www.vsao.org

Erin Hoppe, MA, Executive Director
Jessie Glover Boettcher, PhD, Research Assistant



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'I think a one-time activity doesn't have quite the impact, because for someone with autism, they need to get used to something. They need the repetition.'

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Executive Summary

Research Question

The Ohio Arts Council commissioned VSA Ohio, the state organization on arts and disability, to design and implement activities associated with the first phase of the Autism Spectrum Disorder (ASD) Initiative. The Initiative's primary purpose is to better understand how the Ohio Arts Council can better support children and young people with ASD. Activities were to include the facilitation of round table focus groups, preparation of a report based on analyses, and identification of next steps for the second phase of the initiative.

VSA Ohio designed a research study which utilized the following methods to collect data: literature review, online survey, focus groups, and individual interviews. While limitations to the data exist, numerous themes and ideas emerged which can inform planning for Phase II of the Arts & Autism Research Initiative.

A review of the literature informed data collection and analysis. The literature available on autism, the arts, and their intersection is both diverse and limited. Research, policy, and practice related to Autism Spectrum Disorders continue to evolve and yield new implications. The arts and associated outcomes/benefits have been long studied, but there is a large void in the research related to *arts and disability*. This report's literature review discusses Ohio's position within broader cultural trends, provides an introduction to Autism Spectrum Disorder, describes only some of the researched benefits of the arts, and the intersection and current publications surrounding arts and autism.

The data analysis chapter of this report is divided into four categories: the *Benefits* of bringing together arts and autism, the *Problems and Challenges* around the integration of art and autism, broad *Solutions* to these problems, and the *Role of the Ohio Arts Council* in facilitating more and better opportunities for children and young people on the spectrum. A final chapter outlines conclusions drawn from this research and nine (9) recommendations to the Ohio Arts Council on potential areas for focus, impact, and operations during Phase II of this Research Initiative.

Key Findings

The researchers commend the Ohio Arts Council's leadership and initiative in facilitating opportunities for those with Autism Spectrum Disorder to access the arts. This study is one of the first of its kind in the nation and sets a stunning example for other state arts agencies and cultural bodies of influence to think about access for a new generation and type of underserved audiences. Throughout the research process, VSA Ohio was continuously met with excitement and positive reactions to the project. Without a doubt, the intersection of arts and autism is (or will soon be) an important

topic for millions of Americans. Numerous themes emerged from the research, representing challenges and solutions.

Information about arts opportunities for people on the spectrum is essential, but generally absent. The information void exists for most stakeholders (caretakers of those with ASD, cultural institutions, educators, funders). In part, because the field of autism is fairly fluid, and because the larger society has been slower to keep pace with the field, the information, resources, trainings, and networks that facilitate arts access are underdeveloped and/or under-distributed. The desire to find this information exists on behalf of most parties.

Specialization is often a requirement when working with people with ASD, as its manifestation in each individual is quite different and the term “spectrum” could not be more accurate. This means the potential benefits of the arts for a person with ASD are broad. But it also creates challenges in society, where generalization is often a necessity for health policies, professional development for educators, quantitative research, and more.

Preparation and its impact on fostering positive outcomes must be considered. This means cultural institutions, artists, and educators need to be prepared with lessons and behavior management strategies which account for a range of needs and learners. It also means that individuals with ASD, their parents, and their “team” of caregivers need to take measures to prepare an individual with ASD to be ready for a new, sometimes intimidating, situation. When those with ASD are better prepared for what to expect, such as through a “social story” strategy, the person is less overwhelmed and focused on getting through (or out of) an experience, and can begin to enjoy.

The *Process* of art-making is not always privileged, but it is perhaps the arts-experience component which yields the largest return for an individual with ASD. Frequently, funding for arts and culture activities or arts education offerings emphasizes a culminating event. This might be so “the kids have something to work for” or so “the community and parents can see the benefits.” However, for those with ASD, process, repetition, and practice are what foster positive outcomes related to communication, socialization, behavior, and learning.

Access is a constant challenge for people with disabilities and for cultural institutions. Barriers to access include finances, transportation, geography, perceptual, and physical, etc. For families of children with autism, financial resources are tight and most must prioritize basic health/education needs (eg. occupational therapy) over the arts, which may be seen as a “luxury.” Cultural institutions are charged with reaching underserved audiences and breaking down barriers (see the Ohio Arts Council’s grant application and reporting requirements for confirmation). While many efforts are being made to reach racial, ethnic, and low income individuals, cultural institutions are not overwhelmingly thinking about disability as an underserved community. These institutions need to be willing to prioritize access accommodations (which often include direct costs), then market those opportunities to disabled audiences.

Sustained & Substantial Investments seem to make a difference. Respondents overwhelmingly agreed, and the literature has begun to reinforce, that long-term, in-depth investments will make stronger and more valuable impact on individuals with ASD and the educators, artists, and cultural institutions which provide opportunities. The nature of ASD is such that repetition and structure aid in overcoming components of their disability. When valuing potential returns on investments, these types of experiences will likely yield more than short, sporadic offerings.

Collaboration is key to success when it comes to serving individuals with ASD. This is seen in the “team” assembled for a young person with autism (parent, sibling, occupational therapist, physical therapist, speech therapist, physician, educator, aide, etc). This is seen in the benefits cultural institutions discover when they create new and dynamic partnerships. This is seen in the efforts that will be needed to make the arts more accessible for youth with Autism Spectrum Disorder.

Advocacy by those at the top of organizational hierarchies and grassroots at the bottom alike will increase access by increasing awareness and knowledge. Sending a sustained, cohesive message to Legislators and stakeholders about the integral role the arts can play in the lives of young people with autism, families, and communities can create systemic changes when shrewdly presented during open policy windows.

Summary of Recommendations

The Ohio Arts Council can have a strong and lasting impact at the intersection of arts and autism. The following recommendations are elaborated on in this report’s final section. Recommendations are classified in two categories, which take into account feasibility, investment, and impact.

Green Recommendations can be accomplished during Phase II and over the next few years, require moderate investment, have a direct impact, and yield strong returns on investment

Blue Recommendations can be considered long-range, strategic planning goals, primarily resulting in positive policy and systemic changes

1. **Continued Research**
2. **Task Force Development & Convenings**
3. **Data Collection & Resource Development**
4. **Grant-making Opportunities**
5. **Professional Development**
6. *Advocacy*
7. *Empirical Research*
8. *Arts & Autism Residency Program*
9. *Collaboration with Education & Health Fields*

Introduction

How can the Ohio Arts Council (OAC) better support children and young people on the Autism Spectrum?

The spark for this research project came in the form of a phone call. A mother contacted the OAC's Deputy Director seeking information on arts opportunities for her son, who is on the autism spectrum. Answers were sought from colleagues, including the OAC's ADA Coordinator, who is also the mother of a child on the Spectrum. The discussion revealed a gaping hole, and great opportunity. There are currently no OAC-funded arts projects targeted specifically to children with Autism Spectrum Disorder, and no known hub of information to find these answers.

As a state agency funded by the State Legislature and the National Endowment for the Arts, the Ohio Arts Council is dedicated to funding and supporting quality arts experiences for people and communities. The OAC serves as a clearinghouse for information about the arts in Ohio. Further, the OAC has an ongoing commitment to funding arts learning programs that bring quality arts education experiences to Ohioans of all ages and abilities.

The Ohio Arts Council engaged VSA Ohio to begin Phase I of this research initiative in the fall of 2012. The OAC and VSAO have been long time partners in working creatively to make the arts more accessible for people of all ages with disabilities. It is worth noting that VSA Ohio has experienced similar increases in requests for services and has only a slightly higher capacity than the Ohio Arts Council to connect constituents with cultural opportunities either inclusive of or specifically for (young) people with Autism Spectrum Disorder.

To date, the researchers have been unable to identify a similar research initiative anywhere in the country. There are innumerable institutions, programs, and individuals who are working to make the arts accessible to people with autism Spectrum Disorder. However, no other statewide initiatives or leaders are pursuing this question of arts-access-autism with similarly broad perspectives and/or goals.

Please note that throughout this report Autism Spectrum Disorder, ASD, on the spectrum, and autism are used interchangeably.

The images used in this report were the result of one of VSA Ohio's Adaptation, Integration and the Arts residencies at Helping Hands Center for Special Needs in Columbus. The residency partnered teaching artist Keo Khim with educators to develop an integrated, Universally Designed for Learning lesson on photography and earth sciences lesson for five K-2 classrooms of students with Autism Spectrum Disorder. Images are of the residency in action and pictures taken by the students.

Acknowledgements

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- Mary Campbell Zopf, Deputy Director at Ohio Arts Council
- Jessie Glover Boettcher, Research Assistant for VSA Ohio
- Erin Hoppe, Executive Director of VSA Ohio
- Sharon Malley, Special Education Specialist with the Office of VSA and Accessibility at The Kennedy Center
- Chiquita Mullins Lee, Arts Learning Program Coordinator at Ohio Arts Council
- Kimberley Turner, Grants Office Associate and ADA/504 Coordinator at Ohio Arts Council
- Elizabeth Weinstein, Public Information Officer at Ohio Arts Council



Methodology

The primary research methodology for this project is qualitative. Several data sets were gathered and analyzed to formulate the recommendations laid out in this report. VSA Ohio was contracted to conduct focus groups to gather information about the research question. However, in order to contextualize the study and gather more information from Ohioans, a literature review and online survey were added to the research methodology.

Literature Review

A broad review of published literature was conducted in order to contextualize the overlapping fields of arts and autism. Because the field of autism is evolving and publications connecting it to the arts are relatively new, the broadest sources of literature were considered. Literature sources reviewed include peer-reviewed journal articles, published books, existing websites related to the topics, and information published by media sources. It was also determined that a review of related topics of general disability, autism as a disorder, and demographics would assist with framing the research. This literature review served as a foundation for framing methodologies, findings, and recommendations.

For the purposes of advancing this research initiative, and the public good, a brief annotated bibliography of pertinent and helpful literature is included as Appendix 3.

Online Survey

According to Joel Evans and Anil Mathur, major strengths of online surveys include: larger reach, flexibility, speed/timeliness, convenience, ease of data entry/analysis, question diversity, low administration cost, ease of follow up, controlled sampling, control of answer order, and required completion of answers.¹ VSA Ohio employed an online survey to collect data from a wider sample of Ohioans than just focus groups.

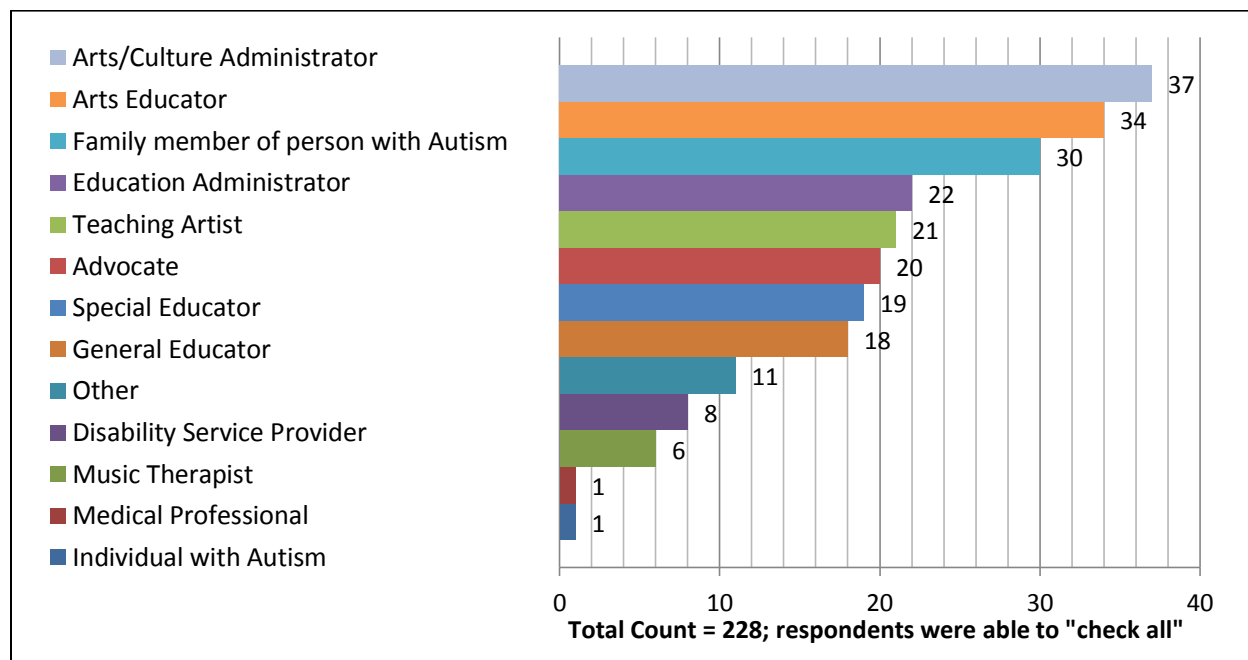
VSA Ohio used Google Forms to create the “Arts & Autism in Ohio Constituent Survey,” which was housed on the VSAO website. The survey was promoted via social media, and an email version was distributed to VSAO’s listserv, the Ohio Arts Council’s Online Grants Application (OLGA) system listserv, and the OAC’s Arts Learning listserv. All emails encouraged respondents to forward and share the email with others. The survey was open from May 29 through June 14, providing 16 days to collect responses. A copy of the survey is included in Appendix 1.

¹ Evans, J.R. and Mathur, A. (2005), “Value of online surveys,” *Journal of Internet Research*, 15(2), pp. 195-219, Emerald Group Publishing Limited. Accessed shlee.myweb.uga.edu/onlinesurvey/valueofonlinesurveys.pdf

Despite the potential for a global reach, this survey did not achieve those results. Of the approximately 2,000 individuals who directly received the survey, and an unknown number who viewed the survey through social media postings, only 119 people responded, approximately 5 percent. Evans and Mathur do note that major potential weaknesses of the online survey include: perception as junk mail, skewed attributes of Internet populations, respondent lack of online experience, technological variations, unclear answering instructions, impersonal nature, privacy issues, and low response rates.²

This low sample size means drawing distinct and specific results is not advisable. However, based on responses, certain themes did emerge, and often more than half or two-thirds of respondents concurred. The sample reflects a low representation of people who actually have ASD or are in the medical profession. Further, questions about familial identification did not ask which type of relative (ie. parent, sibling, uncle, caregiver). These limitations are likely the result of the type of constituents on the distribution lists. Future constituent surveys should consider wider distribution, such as to the health field and ASD support groups, with a longer survey “open time.” This survey also neglected to request demographic information such as zip code, which prevents data from being analyzed by location or access to opportunity. This effectively treats Ohio as an undifferentiated population.

Chart #1. Survey respondent self-identifiers



² Ibid

Focus Groups

Three focus groups were convened in June 2013 and included groups of six, nine, and ten- a total of 25 people. Individuals had a common interest in the research topic, but are generally unfamiliar with one another. An outside facilitator was sub-contracted in order to create a permissive and nurturing environment that encouraged different perceptions and points of view without pressuring participants. Focus groups are used in order to understand how certain groups of people feel about a topic, to provide greater insight into why opinions are held, and produce new insights for developing strategies.

The Facilitator for each session was Dr. Sharon Malley, Special Education Specialist at the VSA and Accessibility Office at The John F. Kennedy Center for the Performing Arts. Dr. Malley was selected for her national perspective, expertise in the fields of arts/education/disability/autism, experience leading focus groups, and professional connections between VSA Ohio and the VSA national office at The Kennedy Center. VSA Ohio's Executive Director and Research Assistant attended all three sessions. A single, different representative from the Ohio Arts Council was also present at each.

Sessions were held in three distinct locations: Ohio Center for Autism and Low Incidence (Columbus, June 5); Xavier University (Cincinnati, June 6), and The Beck Center for the Arts (Lakewood/suburban Cleveland, June 7). Each session lasted from 9:00am until 12:00pm. Each session was audio recorded and transcribed for accuracy and analysis. All participants signed audio recording waivers and received a \$50 honorarium for their time and travel.

Although efforts were made to include individuals interested in the topic, but who could speak from multiple points of view, the focus groups erred heavily toward representation by therapists and service professionals. Several parents were included and three individuals with Autism Spectrum Disorder participated. However, few cultural administrators with limited experience serving people with ASD were included. As a result, conversations occasionally drifted toward participating professionals' current issues and not to broader possible solutions within the Ohio Arts Council's capacities. With assistance from the Facilitator and VSAO staff, conversations were redirected and specific themes did emerge. Further, roundtables overrepresented urban areas (the three C's of Ohio: Columbus, Cincinnati, and Cleveland).

This meant issues related to availability and geographic challenges related to accessing cultural opportunities were diminished. Conversations with participants from rural Ohio areas may have had significant differences.



Focused Interviews

A significant means for the Ohio Arts Council to increase access to arts and cultural activities is through their work with cultural organizations and grant-making programs. This means that one of the primary questions driving this research was how the OAC can affect programming and policy relating to institutions. When it became clear cultural administrators were underrepresented in focus groups, VSA Ohio's Executive Director and Research Assistant sought to conduct individual interviews with this audience. An effort was also made to identify administrators in rural areas at institutions of varying size. Phone interviews were conducted with four (4) cultural administrators. Questions were guided by the online, Arts & Autism Ohio Constituent Survey, but varied based on the individual's experiences and professional expertise. The researchers acknowledge limitations of a small sample size, the results of two different individuals conducting interviews, and a lack of recording for accuracy (however, notes were taken).

The Literature

About Ohio

As this research initiative appears to be unique, this section is intended to consider Ohio in the broader context of national demographic trends. Ohio is considered by many to be a microcosm of the nation, or, “Middle America.” Since 1904, Ohio voters have correctly picked the winning presidential candidate 25 out of 27 times, including 14 in a row.³ Columbus, Ohio has been called “Test City, USA,” for companies marketing new products because it represents broader trends of the nation, its central geography, and representative demographics.⁴

The United State Census Bureau provides the following demographic data for Ohio.

- The population of Ohio in 2012 was 11.54 million people, a growth of 1.6% since 2000.⁵
- Of those, 23% are under 18 years old and 14.8% are people ages 65 and over.
- 87.8% of people age 25 and over are high school graduates.
- 24.5% of people age 25 and over have a bachelor’s degree or more.
- 6.5% speak a language other than English at home.
- 83.5% of the population is White (higher than the 77.9% national average)
- 12.5% is Black/African American (lower than the 13.1% national average)
- 3.3% is Hispanic or Latino (lower than the 16.9% national average)

Ohio represents 40,861 square miles on the eastern side of what is considered “Midwest” America. Although it is often thought of as a rural state, Ohio’s average persons per square mile (282.3) is more than three times the national average (87.4). Of its 88 counties, 32 are considered Appalachian, where nearly 18% of the population resides.⁶ The 2010 U.S. Census numbers also indicated Ohio’s population is shifting away from industrial centers and rural areas in the northern parts of the state to suburbs around Columbus and Cincinnati. Of Ohio’s ten largest cities, Columbus is the only one where population has increased (up 10.6%). Decreases range from 4.7% in Parma to 9.7% in Canton to 17.1% in Cleveland.

The American Community Survey is an ongoing statistical survey that samples a small percentage of the population every year and administered by the US Census Bureau. It is considered to provide the most detailed and up to date statistics about the incidence of disability in America. According to the 2011 survey, the incidence of disability, ages 15 and up, in Ohio is 13.3%, just slightly higher than the 12.1%

³ PolitiFact (2010), “Ohio’s voter opinions a steady bellwether for presidential elections.” Accessed, www.politifact.com/ohio/statements/2010/jul/23/john-kasich/ohios-voter-opinions-steady-bellwether-presidential/ one July 3, 2012.

⁴ Conan, N. (2009), “Columbus, Ohio: ‘Test City, USA,’” National Public Radio. Accessed www.npr.org/templates/story/story.php?storyId=113795356 on July 3, 2013.

⁵ State and County Quick Facts, Ohio; United State Census Bureau, U.S. Department of Commerce. Accessed, <http://quickfacts.census.gov/qfd/states/39000.html> on July 3, 2013.

⁶ About Appalachian Ohio, <http://www.oache.org/about/appohio.php>

incidence in the United States.⁷ Ohio is ranked 15th in incidence (West Virginia is the highest with 18.9% and Utah is the lowest with 8.8%).

About Disability

There is no single, universally accepted definition of disability. The most frequently applied framework of disability views it as difficulty performing socially expected activities such as employment, and explicitly recognizes the interaction of the environment and pathologies/impairments to cause disabilities. The Americans with Disabilities Act rests upon this framework and recognizes that improvements to the environment (ie. public transportation access, workplace accommodations, social stigma) can positively impact perceptions and experiences of disability and thus improve the inclusion of all people. The current American Community Survey covers six disability types: hearing, vision, cognitive, ambulatory, self-care, and independent-living. A respondent is considered to have a disability if he/she answers “Yes” to any of these six options.⁸

The Individuals with Disabilities Education Act, first enacted in 1975, mandates that children and youth ages 3-21 with disabilities be provided a free and appropriate public school education. The National Center for Education Statistics collects information on children served in federally supported programs for those with a disability. In 2009-10, 13.1% of all enrolled students had a disability.⁹ Learning disabilities was the highest incidence of 4.9%, followed by speech or language impairments at 2.9%. At 0.8%, the incidence of autism ranked 5th (tied with emotional disturbance) in numbers served. This incidence rate has increased 0.1% every year since 1999-2000, when data for autism first became available.

About Autism Spectrum Disorders

An important component of this Initiative is to establish a common understanding of Autism Spectrum Disorder (ASD). However, it should be noted that the definition and understanding of ASD continues to evolve, can vary by field or context, and can serve different purposes. However, all definitions identify difficulties experienced by individuals with ASD in the areas of communication, socialization, and behavior.

As stated in the Ohio’s Parent Guide to Autism Spectrum Disorders, “The umbrella term *pervasive developmental disorders (PDD)* covers a group of five development disabilities that have a neurological basis; that is, they are caused by a brain disorder that affects how an individual thinks, communicates, and interacts with others. PDD

⁷ American Community Survey, 2011, *Percent of People with a Disability - United States and Puerto Rico*, United States Census Bureau. Accessed <http://factfinder2.census.gov/faces/nav/jsf/pages/searchresults.xhtml?refresh=t>.

⁸ American Community Survey History, www.census.gov/people/disability/methodology/acs.html.

⁹ U.S. Department of Education, National Center for Education Statistics (2012). *Digest of Education Statistics, 2011* (NCES 2012-001), [Chapter 2](http://nces.ed.gov/fastfacts/display.asp?id=64). Accessed nces.ed.gov/fastfacts/display.asp?id=64.

includes the following categories of diagnosis: Autism, Asperger Syndrome, Pervasive developmental disorder-not otherwise specified, Rett Syndrome, and Childhood disintegrative disorder.”¹⁰

A medical definition is required for a “diagnosis” of autism and must be made by a medical professional (psychologist, psychiatrist, physician) using Diagnostic and Statistical Manual of Mental Disorders (DSM-V) criteria. The DSM-V was released in 2013 and now uses the umbrella term, “Autism Spectrum Disorders” to include multiple PDD labels. This change will have numerous impacts, which have yet to be fully realized. An educational definition was designed to identify children eligible to receive special services under the Individuals with Disabilities Education Act. School evaluation teams make this identification, taking into consideration how symptoms adversely affect educational performance. Medical diagnoses are not required for the educational definition, nor does a medical diagnosis guarantee special education services.

In March 2013, the Centers for Disease Control released a new report which finds the prevalence of diagnosed ASD is now 2.00%, or 1 in 50, for children aged 6 - 17. This is significantly higher than the estimate of 1 in 86 for children in that age group just four years earlier. Rather than a true increase in prevalence, the authors argue that much of the increase “was the result of diagnosis of children with previously unrecognized ASD” and an increase in recognition by community providers.¹¹ These increases do extend an ongoing trend observed in the United States and other developed countries over the past several decades.

The Ohio Center for Autism and Low Incidence notes on its website, “The incidence of autism is consistent around the globe, but is four times more prevalent in boys than girls. autism knows no racial, ethnic, or social boundaries, and family income, lifestyle, and educational levels do not affect the chance of the occurrence of autism. There is no proven cause of ASD.”



In the early stages of each Focus Group, the Facilitator asked participants of varying backgrounds to briefly describe autism. The following statement was then read aloud in order to align participant understanding.

Autism is a neurobiological developmental disability, generally detected by about age three (pervasive developmental disorder). Autism affects

¹⁰ Ohio Center for Autism and Low Incidence (2009), *Ohio's Parent Guide to Autism Spectrum Disorders*, 2nd edition, developed by Ohio parents, for Ohio parents, pg. 2, Ohio Department of Education.

¹¹ Blumberg, S. J., et al, “Changes in Prevalence of Parent-reported Autism Spectrum Disorder in School-aged U.S. Children: 2007 to 2011-2012”, *National Health Statistics Reports*, No. 65, (20 March 2013), Centers for Disease Control. Accessed June 2013, www.cdc.gov/nchs/data/nhsr/nhsr065.pdf.

sensory experiences, characterized by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. Each individual with autism is very different from others, and there can be a wide range of severity of the disability, from very mild to significant. No one cause has been identified, but rare gene changes can cause a predisposition. Environmental stresses play a part, such as age of parent and difficulties at birth. Scientists are currently looking at immune system influences. The main categories for difficulties people with autism might experience are sensory, communication, and social/emotional.

An Autism Spectrum Diagnosis has significant implications for parents, families, and caretakers. Because of its impact on early developmental milestones, children with autism are generally diagnosed before the age of four. However, other pervasive developmental disorder symptoms are more pronounced as children age and diagnosis may not happen until much later. When a caregiver suspects a child has autism, he/she must acquire a number of evaluations, educate him/herself, find services, and keep accurate records. Diagnosis is just the beginning. Daily life changes for families; a host of interventions and social service agencies must be sought; specialized education services are needed; and new issues must be considered when planning for the future. In short, caregivers must dedicate substantial time, emotion, and money to become experts and advocates for their child.

The intricacies of Autism Spectrum Disorder mean that there are numerous identifying traits, diagnoses, services, and prognoses. The term “spectrum” is essential to understanding individuals, the field, and the implications for practice and policy.

If you've met one person with autism, you've met one person with autism.

-Stephen Shore, adult with ASD and Autism Expert/Presenter

About Arts Benefits

The Ohio Arts Council asserts that the arts are part of the solution for a better Ohio. This is a sentiment echoed by artists, educators, and advocates nationwide. Countless research efforts have been undertaken to demonstrate, among other things, the capacity of the arts to revitalize communities, increase the quality of life, build tolerance, create jobs, and prepare young people to be engaged citizens and productive members of a 21st century workforce. This research initiative seeks to primarily support students and young people with Autism Spectrum Disorder. Therefore, the emphasis in reporting here is on the benefits of arts education and experiences for individuals with disabilities.

An Americans for the Arts Fact Sheet about the Benefits of Arts Education include the following findings.¹²

- Stimulates and develops the imagination and critical thinking, and refines cognitive and creative skills.
- Has a tremendous impact on the developmental growth of every child and has proven to help level the "learning field" across socio-economic boundaries.
- Strengthens problem-solving and critical-thinking skills, adding to overall academic achievement and school success.
- Develops a sense of craftsmanship, quality task performance, and goal-setting—skills needed to succeed in the classroom and beyond.
- Teaches children life skills such as developing an informed perception; articulating a vision; learning to solve problems and make decisions; building self-confidence and self-discipline; developing the ability to imagine what might be; and accepting responsibility to complete tasks from start to finish.
- Nurtures important values, including team-building skills; respecting alternative viewpoints; and appreciating and being aware of different cultures and traditions.

The physical and sensory impact of arts education has also been noted, and is of particular importance for individuals with disabilities.

- A student making music experiences the “simultaneous engagement of senses, muscles, and intellect. Brain scans taken during musical performances show that virtually the entire cerebral cortex is active while musicians are playing.” (*Learning and the Arts: Crossing Boundaries*, 2000, p. 14)
- Regular, frequent instruction in drama and sign language created higher scores in language development for Head Start students than for a control group. (*Young Children and the Arts: Making Creative Connections*, 1998, p. 1)
- Dance helps build motor control, body relationships, and a sense of direction. (*Young Children and the Arts: Making Creative Connections*, 1998, pp. 11-12)
- Music teaches children about rhythm, sound and pitch. Beats can help children learn rhymes and other features of reading such as phonological awareness. Using repetitive songs to learn academic facts (like the alphabet song or multiplication tables) can make the learning experience easier and more fun. (National Center for Learning Disabilities, Editorial Team)
- Drawing and painting reinforce motor skills and can also be a way of learning shapes, contrasts, boundaries, spatial relationships, size and other math concepts. (National Center for Learning Disabilities, Editorial Team)

It is worth noting that while research about the effects of arts learning and engagement on students is prolific, there are few studies that specifically and methodically assess the impact on individuals with disabilities.

¹² Americans for the Arts, 2002, Benefits of Arts Education. Accessed www.americansforthearts.org/get_involved/advocacy/funding_resources/default_005.asp on July 18, 2013.

About Arts & Autism

There is a growing body of literature on the integration of art-making and art experiences into the lives of children and young people with Autism Spectrum Disorder (ASD). The existing literature falls into a number of categories, and the following are represented here: general information on arts' impact on children and young people with ASD, popular media and human interest stories on Autism and the arts, tools and strategies for including children with ASD in a classroom or school setting (with special attention to a student mix of ASD and neuro-typical children), best practices and outcomes of music therapy, and benefits and outcomes of other arts-based therapeutic approaches. There is also a small but growing literature on tactics and strategies for creating sensory-friendly environments for arts experiences.

The literature is scattered across a diverse collection of publications (from academic and professional journals to popular news media to practical education guides) and written for an equally diverse set of audiences (parents, arts educators, school and cultural administrators, and, importantly, the general public). Additionally, various publications operate according to very different measuring sticks and sets of priorities. For instance, some aim to help establish certain practices as useful or therapeutic by adding to a body of empirical data, while others work to establish a connection between the tendencies of people on the spectrum with the art-making process, and others operate as persuasive, storytelling advocacy tools.



The appended bibliography organizes some of the most prominent contributions to the literature into the categories mentioned above and annotates each entry. Note that there is an extensive literature on inclusion strategies and strategies for engaging people with all kinds of special needs that are not addressed here, though there are certainly overlaps in useful tactics, arts-based outcomes, and non-arts-based outcomes.

The general information literature meets a broad grouping of needs, including the need for greater awareness about autism and how it impacts families. Additionally, this literature works to expose readers to the arts creation experiences of people on the spectrum, articulates connections between the predilections of people on the spectrum (such as visual thinking or even executive functioning) with art-making to locate strength on the spectrum, and does some work to articulate the value in arts experiences for a mixed group of people with ASD and neuro-typical individuals. Though the general literature is wide-ranging and strong, one gap for future exploration is that there is relatively little research on the value of arts experiences (as opposed to arts participation), and specifically inclusive opportunities.

The issues and opportunities that impact people on the spectrum have increasing presence in popular media. Some of these articles aim to expose innovative opportunities for people on the spectrum, such as art exhibits, research, and even films that have been created about arts spaces that serve people on the spectrum. Also, there are articles that tease out some of the cultural and systemic issues at stake in the lead-up to and in the aftermath of the adjustments to the diagnostic criteria for ASD in the fifth American Psychiatric Association's Diagnostic and Statistical Manual (DSM-V).

There is a great deal of work in the realm of tools and strategies for engaging children and young people on the spectrum in art-making experiences in the classroom. This is especially prevalent when looking at the general-education context when students are mainstreamed into a classroom for arts classes. These articles are highly accessible and practical and are often aimed at teachers who may have very little exposure to the particular child, to the nuances of autism, or to experiences implementing an individualized education program (IEP). There is a slight preference in this literature for strategies that are useful in the music classroom, though many of these strategies are simple to generalize to other arts contexts. Notably, this category is focused on providing accommodations for children who are still school-age.

The literature on arts-based therapeutic options for children and young people with ASD focus on the positive benefits of engaging in art-making or creative processes in a formal, professional therapeutic context. These benefits are framed primarily in relation to the primary differences and deficits associated with ASD and so outcomes that are identified are usually in concert with this. For instance, outcomes might include increased eye contact, increased capacity for joint attention, and conversation benefits. Taken as a whole, the field of music therapy aims to position itself as a therapeutic option on par with the more broadly-used options of occupational, physical, and behavioral therapy. There are articles in a wide range of academic journals and at least one professional anthology has been published in the past year. The music therapy field is housed especially in the national organization, American Music Therapy Association (AMTA).

In contrast, other therapies have comparatively little scientifically validated data. As a result, no non-music-based arts therapies are identified as well-studied therapeutic options for autism. Though there is work on the value of art making experiences, the literature appears to be several years old and primarily pointed at ways that therapists and behavioral consultants who may not be arts-trained can use art projects in their therapeutic context. National entities are not as robust as the AMTA and are not as focused on autism as a strategic issue but include the American Art Therapy Association and American Dance Therapy Association. There is a smaller field called "Movement Therapy" which is more focused on generating benefit for people with ASD, but which does not yet appear to have a national presence.

The arena of sensory-friendly environments for art experience is very underdeveloped in the literature. The balance of the literature around art and autism is most definitely tipped toward art-making experiences as opposed to arts participation experiences. The few pieces of literature that exist are informative articles about specific opportunities (for instance, in Washington DC and New York City) and a resource guide published by the Kennedy Center. More literature is needed as organizations work to establish best practices.



Data Analysis

For the purposes of this report, the themes that emerged in the focus groups and online survey results can be collected into four categories: the **benefits** of bringing together arts and autism, the **problems and challenges** around the integration of art and autism, broad **solutions** to these problems, and the **role of the Ohio Arts Council** in facilitating more and better opportunities for children and young people on the spectrum. The data analysis section of the report is structured into these four categories. Additionally, the respondents in the roundtables and survey came up with **ideas** for how the Ohio Arts Council and VSA Ohio can be involved in serving children and young people with autism and their families; many of these ideas are reflected in the recommendations section of this report.

Benefits

Spectrum strengths

Many respondents lingered on the strengths and other qualities people with ASD bring to art experiences and art-making. A critical part of understanding these assessments is a clear awareness that different individuals with ASD can have vastly different experiences and skill-sets, so any generalization must be taken advisedly.

Some individuals with autism can be described as “twice exceptional”--in addition to their autism diagnosis they may have exceptional abilities in a particular art form. Focus group respondents shared stories especially relating to music and visual art. For instance, more than one music therapist chose her career after an opportunity to work with a young person on the spectrum who had perfect pitch. Another respondent shared a story from the founder of her organization who met a man with autism who had created a massive collection of art. Another teaching artist, a visual artist, suggested that these talents can “hide” for years in children or young people on the spectrum until someone is positioned to help draw those talents out.

Several respondents, though, offered a corrective to the notion that all people with autism demonstrate savant-like skill in some art form. They did purport that art experiences remain valuable for those people with ASD who do not exhibit great skill. One mother stated that craft classes have created “a nice opportunity for [my daughter] to develop leisure skills.” A music therapist suggested that her participants who are on the spectrum occupy a “spectrum of contribution” in class and elsewhere. Several people at the roundtables shared stories, like the one of a child who, after a long period of difficult engagement, had a breakthrough (drumming on beat or speaking a line of theatrical dialogue) that functioned as an achievement for the individual and sometimes even for a whole class.

A number of participants considered the different ways of knowing inhabited by people on the spectrum that bring value to their own art-making and can bring value to others with whom they may collaborate. One roundtable respondent, who runs a small theatre company for people on the spectrum, suggested that many aspects of a common autism diagnosis (such as “plays intently for abnormally long periods” or “is overactive”) can be viewed as presenting positives for theatre work. Another participant, the mother of a boy with autism, suggested that art-making allows children on the spectrum to release “the creativity that’s in their mind...in a way they can communicate.” Another respondent, an education coordinator for an organization serving people with disabilities, suggested that, if one is paying attention or conducting the right kind of research:

You can show ... art is not just therapy, art is not just for students with disabilities - the benefit is both here [with students with disabilities] and here [with mainstream or neuro-typical students]. And these students who happen to have disabilities are making this benefit for a student without a disability more explicit.

Art strengths

Respondents also articulated many benefits that art can bring to people on the spectrum. Some, but not all, of these benefits are reflected in the literature as “arts-based outcomes” of arts participation and arts experience. In the Arts & Autism Online Survey, respondents identified a wide range of mediums as having the potential for creating positive outcomes (Chart #2). Participating in visual arts and music classes were the most prevalent. Attending music, theatre, of dance performances ranked higher than attending museums and festivals. The survey asked about the outcomes themselves, which were equally diverse (Chart #3).

Chart #2. Arts experiences yielding a positive outcome for kids with ASD

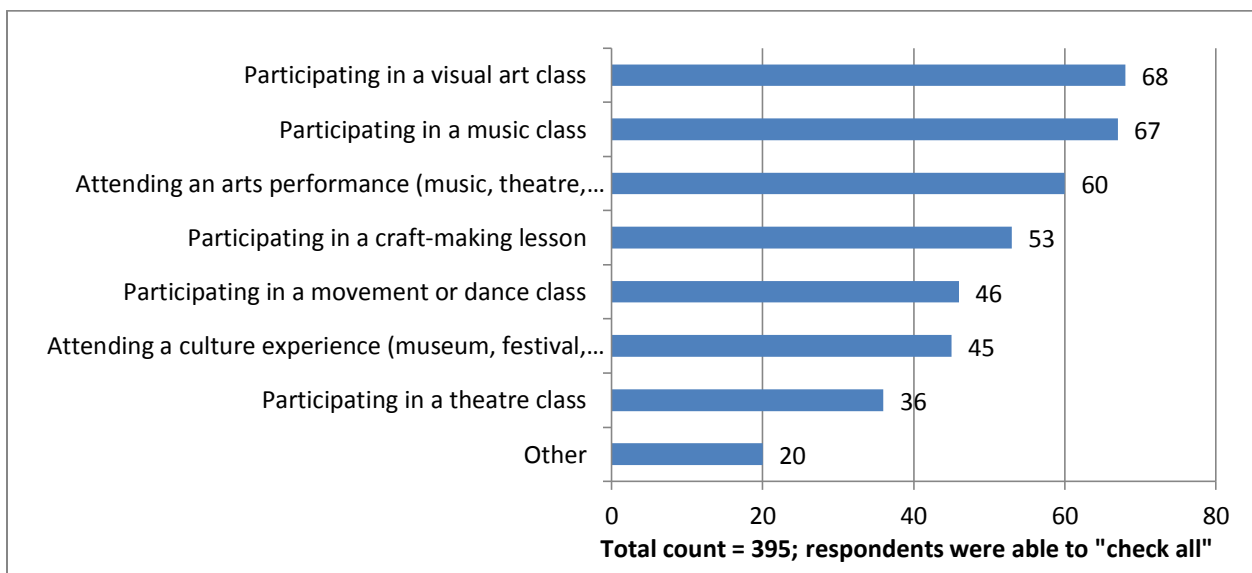
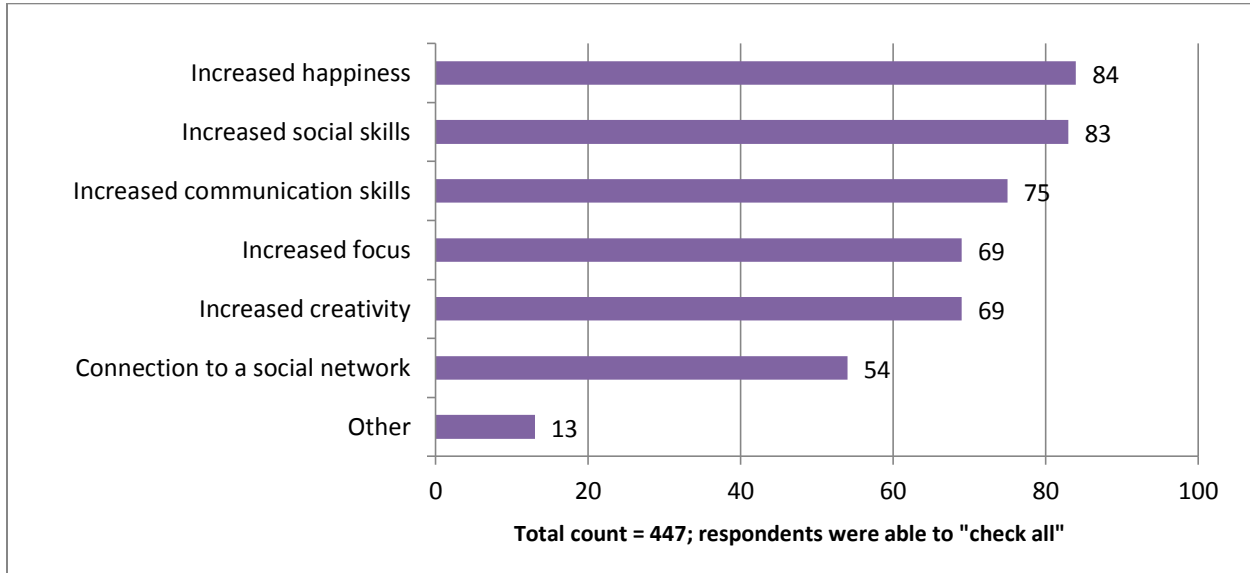


Chart #3. Benefits observed when kids with ASD engage with the arts



Communication can often be a challenge when working across the lines of difference between people on the spectrum and neuro-typical individuals. Therefore, respondents emphasized art's capacity to help participants and facilitators find a common language around which they can connect. One behavioral analyst works with many art-based strategies in her work and says that she feels like "it's a way to understand what's going on inside...that individual's head if they can't tell you, and it's a way to connect and form relationships in a way that you can't, maybe, through talking and then writing. So I feel like it...forms this deeper connection." An educational consultant with a background in arts education recounted a story of a child with Autism who dealt with a great deal of social anxiety but responded positively to the suggestion that he draw about what makes him anxious in any given situation. "You know, when he was feeling anxious about something he would pick a piece of paper and we'd talk about what he drew....it was a release for him."

In many different contexts, the "quirkiness" of people who are drawn to pursuing art was seen as a virtue when working with children and young people with autism. The implication of these statements is that all artists/arts educators are considered "different," "other," or "quirky" by society, therefore they are more prepared than others to relate to and draw out kids on the spectrum. One teaching artist who is also the director of a small nonprofit arts organization reflected on his work with a student on the spectrum in this way: "Had [the child's mother] not told me that [the child] was on the spectrum...I probably would have said, 'Yeah, he's a pretty quirky kid, but....' I really didn't think anything of it." A teaching artist argued, "We have this whole value system that says arts are other, you know. And we have this whole value system that says that anybody with disabilities are other...so I think we naturally see that those things can work together."

A common consensus in the roundtable groups was that artists are natural teachers and have something distinct and specific to offer children on the spectrum. This is, in part, related to the point about “quirkiness” above. One teaching artist stated, “I’ll speak for myself, but I think...most artists are just generally sensitive, you know? And...there is training that probably needs to happen, but I think we go into a room just feeling a little different.” Another respondent, the father of a daughter with Autism, suggested that artists should be actively educating decision-makers and funders about the impact of their work too.

I think an artist will walk into a room and they don’t care that the kids are Autistic. They have no judgment about it - they came to do the painting, to make the music, to whatever. And I think...a lot of autistic children respond to that. There’s some bell in their head that says, ‘this person doesn’t think I am weird or unusual.’

Another teaching artist talked about her experience taking children with autism through a theatrical process and learning that loving her students meant “not bringing my stuff into the space, and just letting it be ‘what can I learn from you guys, and how can we work synergistically?’” She went on to describe one iteration of the class where therapists replaced actors as the teachers/facilitators in the room, and the class wasn’t as effective. “The therapists were very result-oriented, and they weren’t very human-play oriented....I don’t mean to generalize about therapists, but that’s just what our experience was.” It’s important here to note that many of the therapists in the room identified great experiences where they have allowed the process of art-making to come to the surface and benefit a child with ASD.

This perspective was strong across boundaries of people’s specialties in the room. However, several people suggested that these “natural” capacities do have limits. One autism advocate who runs an education organization recounted an experience of artists with no experience or background walking into a room full of children with ASD, cautioning, “There’s no telling what you’re going to get, but you’re going to see autism.” Another participant, a teaching artist focused on theatre, said that through experimentation and observation she has noted that “some [actors] aren’t particularly effective in this work,” especially those who are more concerned with creating a product based around their own skilled technique than they are with connecting with the children in the room. And another educator with training in visual art noted how much she felt like a failure when students with autism were not using materials and taking instructions and guidance as expected. However, she was able to learn a lesson from this experience: a flexible process is more important than a predetermined product.

In art, the hands and body get involved - art experiences have sensory and multi-sensory components. A great deal of attention has been paid to the sensory sensitivity of many people on the spectrum, and the needs of individuals should always be kept in mind. But it is in fact the sensory qualities of different art forms - the physical interaction with materials and tools in visual arts, the invitation to jump and move in

theatre and dance - that are often helpful for people on the spectrum. One theatre practitioner identified her observation that people on the spectrum often need to get up and move around as the reason she started a theatre company for people with dual diagnoses. Another respondent noted that one of the reasons that academic settings present challenges is the practical requirement for long periods of sitting, when “our people need to be up and moving.”

Specifically, some respondents suggested that behaviors like “stimming” and perseveration, which often present challenges, sometimes serve as art-making strengths, impacting process and product. “Stimming” is a slang word that describes the act of using a repetitive body movement to self-stimulate and calm, and can create a benefit for some students when they are working with materials in a physical way. The father of a child with autism observed that his son gained some of the same benefits from working with materials like clay or paper and glue (materials that involve pressing and manipulation with the fingers) that he gained from some other self-stimulating behaviors. He also recounted a dance experience when his son’s public school partnered with the local professional ballet company.

My son was able to memorize every dance routine. And it involved a lot of jumping, which helps with the vestibular stimulation - you can wiki that...and he literally, every day, practiced the dance, and it literally helped him deal with being overwhelmed. So instead of kind of flapping and jumping, he was doing dance.”

Perseveration, that is, persistently repeating an activity or verbalizing a statement, can have an impact art-making as well. One theatre practitioner noted that one of her student actresses “perseverates on visual parts of her character.” In this case, this “negative” effect of ASD demonstrated positive focus and interest.

A behavioral analyst who works in a psychiatric setting shared the story of a young boy on the spectrum who presented a magic act for a group variety show, which capitalized on the presenting behaviors of his autism for dramatic effect.

So he had this, this top hat and he has this little script...and he’s you know, shaking his [wand] and he’s looking over here, and people are like, ‘Oh, he’s just, he’s off in his little world - and then all of a sudden he scoops it up, the hat is empty, and everybody goes crazy - because, you know, he looks like...he’s not paying attention, but he was totally thinking, he’s totally there. He knows what he’s doing. It’s just that moment of, we need to assume competence with these clients at all points in time because there’s a pretty good chance they are smarter than you, and they are just working the system.

For many people on the spectrum, art space can become a safe space, a space where their difference is embraced; a space where they can try things or test out ideas; a space where process is encouraged; a space that values the individual but that allows

for courageous risk-taking. One respondent, a vocational counselor for special education students in a city school system, praised an arts-centered high school in her system for being a place where students “were allowed to be who they were, and could find their niche.” One parent proposed, “The arts can be a haven from bullying.” One roundtable respondent, who is himself on the autism spectrum, characterized the value he gets from opportunities to play and rehearse music as “Freedom. Freedom to explore.”

One of the implications of art space as safe space is that it takes time and sustained relationships to build trust, routine, and rhythm, all of which are broadly appealing to an individual on the spectrum. The director of an organization that facilitates autism education emphasized that the value for a child with autism comes out of a long-term process: “I think a one-time thing doesn’t have quite the impact because I think for someone with autism, they need to get used to something. They need the repetition...and I think if there could be some opportunities where they are slowly building...[that would be beneficial].”



Participants in the roundtables and surveys lingered on the value of art-making as a social experience. Art experiences often offer children and young people across lines of ability to have a dialogic encounter with art together in a world where, as one administrator articulated, “a lot of their routine in the community is based around their diagnosis.” Several roundtable participants referred to opportunities to observe two people - one with autism and one without - collaborating together on a musical arrangement. One father of a teenage boy with autism credited art experience with allowing his son to gain contact and even friendships with people in a wide range of generations. “My son doesn’t have a lot of friends, but he invited some of his friends to a birthday party and they ranged in age from 4 years old to 78 years old. And the arts was a part of that.” A music therapist who runs a music studio that serves mostly people with developmental disabilities recounted a story of an ad-hoc situation that rose up in a group at music rehearsal.

One guy was having trouble - his girlfriend kept texting him. And it was causing a lot of anxiety. And so [one of the other guys] started coaching him on that. What you do in that situation? And so this little social skills lesson arose naturally out of that. You know, we helped facilitate it, but the students also took care of it as well. So...those kinds of supports are there - we’re going to stop...the music if need be to address some of these other things that are real life that help us generalize. [She takes on the voice of one of the students in her session] ‘Oh, I can do it - I

feel, I'm really confident in my musical skills so I feel like I have a space where I can discuss those kinds of things so I can generalize it.'

Not only does an art space offer the opportunity for social experiences, it offers a young person with ASD an opportunity for rehearsal for other encounters. Rehearsal and practice are, in fact, universally necessary attributes of art-making and skill-building, and repetition is valuable for many people on the spectrum. One mother and autism advocate noted,

[What is] interesting about the drama, the music, the dance is that...practice is a part of the whole process. And I think that people with autism - they don't get it the first time; many people [don't get it]. And so what's helpful is that this is an opportunity where everyone is practicing. Everyone has to rehearse. Everyone has to get feedback in terms of improvement.

She went on to note that what might seem like "normal" conversation presents a great challenge for many people on the spectrum.

People are not going to say, 'wow, you had a great conversation! That was so good.' They don't know the effort in it - but somehow there's an assumption with the arts that there was a lot of effort put in - which there is. And so there's an opportunity to give some positive feedback - again, that's a natural part of the process.

Another parent of two children, one of whom is on the spectrum, noted that practice is not just a trait of the set-aside art-making space, but can travel home with children after they participate in arts experiences. He claimed, "I don't think there is a single [arts] experience my kids have seen where they haven't tried to do it at home."

Connected to this opportunity for rehearsal is the structure that many art-forms offer: music has rhythm, a set symbol system, and a beginning-middle-end structure; plays have a script; dance steps have a particular shape; visual arts have materials with limitations on what they can do; and crafts come with a pattern or set of instructions. Several respondents emphasized the importance for people with ASD of structure without rigidity, and offered stories of art teachers who tried to force homogeneous creative output as examples of a rigid, non-helpful stance. Conversely, several respondents shared stories of participants on the spectrum who used the medium of drawing to communicate and express themselves when speaking did not suit, or of children who did not exhibit comfort in one-on-one interactions but took the stage confidently with a script in hand or a practiced solo to deliver.

Building on preparation for social encounters, the arts were noted to be an important part of leisure skill development. Though many individuals on the spectrum demonstrate exceptional skill in certain artforms, as one person said, "not everyone is

going to be a maestro,” and many respondents identified value in developing interests and skills that could travel home with a person on the spectrum.

The value of the arts to provide ad-hoc vocational training was cited. One participant, the father of a young woman with autism, urged the rest of the people in the room to remember the numbers of people on the spectrum who are entering or will soon be entering employable years.

The numbers are going to be overwhelming because of the change in the diagnostics and whether you agree with them or not, the fact is, they were changed and the bar was either raised or lowered depending on your point of view. So there are going to be a lot more members of people on spectrum in, in society....I think ten years from now a significant percentage of the workforce is going to be on the...autism spectrum.

One music therapist suggested that a strength of the arts is that it “has a lot to offer as far as being an avenue towards learning” and promotes “process thinking,” which helps individuals in the pursuit of a job. One administrator who works in a context with people of varying developmental disabilities made an observation about his setting that he wished to generalize to apply to people on the spectrum, too.

We have four individuals [who are served in our program] who received part-time employment...that’s better odds right now...than the local voc[ational] rehab[ilitation] program. I mean - it’s like, just based on the skills they were building in the arts, and relationships, and it just happened. We didn’t have to try for them to get this part-time employment, it just...worked.

Participants emphasized the importance of personal/human expression and the unique capacity for art-making experiences to facilitate this expression for people on the spectrum. One man on the autism spectrum praised a teaching artist, a dancer, for her impact.

You’ve planted a seed of...something to feel good about themselves. I mean, that’s the greatest gift you can give. Even if they never dance again. They feel good about themselves and they can do other pursuits and I can’t think of a better gift to give somebody than, than boosting their self-esteem, giving them some means by which to feel successful and good about themselves.

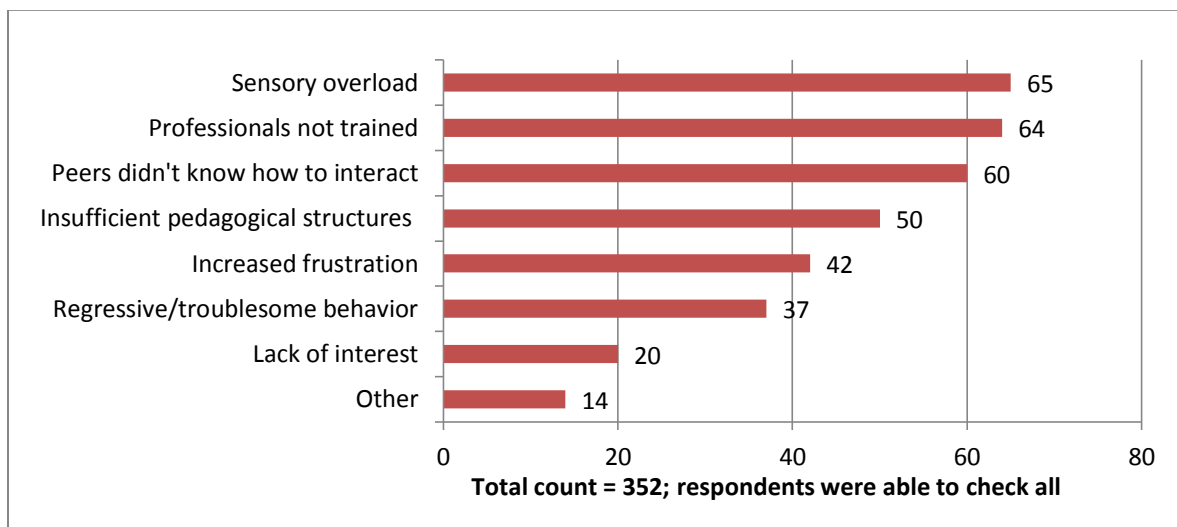
A music therapist and researcher summed up the observations of her roundtable in this way: “What we’re all saying, what I think we all agree [on]...it’s the arts, the process of the arts - that makes us human!”

Problems and Challenges

The spectrum of abilities, skills, strengths, interests, and presenting qualities associated with the autism spectrum itself presents a set of challenges. The spectrum contains inherent diversity. In the evidence-based literature on therapeutic practice, emphasis is placed on individualized treatment. This presents challenges in the general-education classroom where student-to-teacher ratios are stretched and where individual aides are not always available, in artistic spaces where artists and educators may not be prepared for the range of presenting behaviors associated with ASD, and for research where a premium is placed on generalizable knowledge. Respondents suggest that the needs of people on the spectrum call for a longer-term investment rather than a one-time experience. The literature, which focuses on outcomes observed over time, corroborates this observation. However, specially-crafted opportunities in cultural organizations are few and far between, or inconsistently offered.

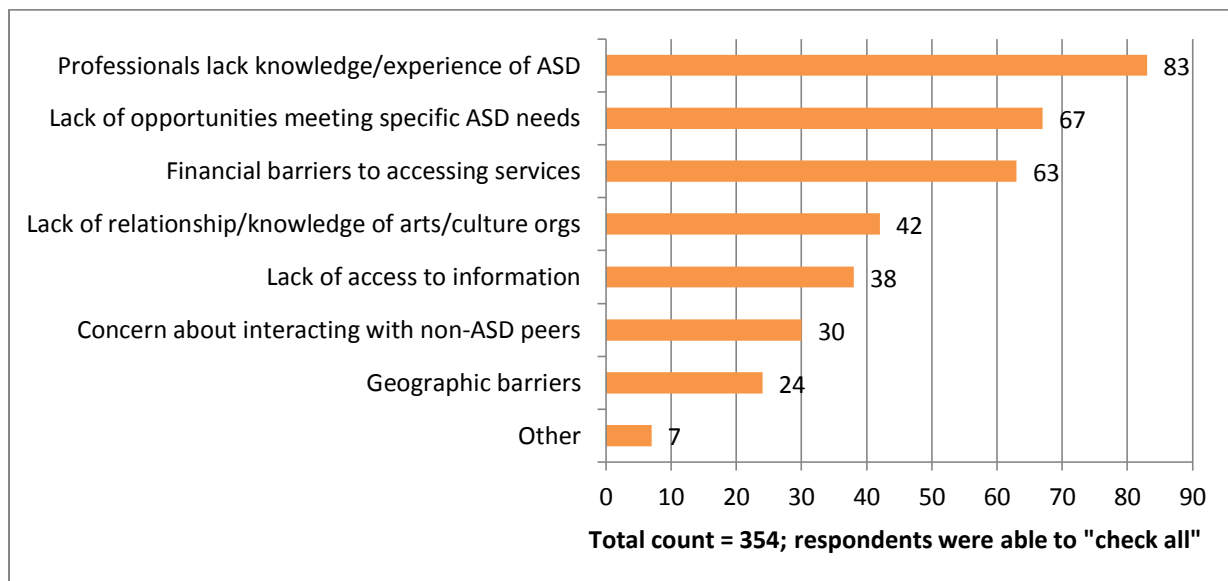
The Arts & Autism in Ohio online survey asked two specific questions about challenges related to arts activities for young people on the spectrum. The first was participant focused, and asked about challenges young people might face when attempting to participate in an arts activity. The most common identified challenge is an individual one (the potential for sensory overload). Closely following was an external one (perceived deficiency in professional and peer training/awareness). One potential limitation to these observations relate to “who” filled out the survey. In focus groups, parents and caretakers tended to cite their own fear of expectation of the child’s behavior. These individuals are both aware of the child’s capacities and have the potential to be (over) protective. Engaging more individuals with ASD to directly answer this question could yield additional clarity. However, cultural administrators also took the survey and noted lack of training and perceived preparedness.

Chart #4. Challenges observed when kids with ASD participate in the arts



The second question asked respondents to note external barriers to participation. The repetition of “lack of knowledge/experience” indicates an area which might be readily addressed. Lack of opportunities might reflect both a lack of access to information and/or an actual lack of programming which meets the needs of individuals on the spectrum. Financial barriers were a consistent theme in all three focus groups. While geographic barriers are cited, the survey did not differentiate between proximity and transportation. These two very different possible reasonings require additional study, but are both certain factors, based on focus groups.

Chart #5. Primary barriers to providing arts experiences for kids with ASD



Access is multi-directional problem. The researchers identified at least five connected but distinct access problems that impact families of children and young people with autism. These barriers to access are: financial, geographic, transportation, stigma, and knowledge. Additionally, the researchers identified at least three access problems for arts organizations that might seek to connect effectively with audiences that include people on the spectrum: knowledge, contact with audiences, and financial. Broadly, our respondents spoke in a far more detailed manner about the former categories, and touched more briefly upon the latter.

Access barriers identified for families and children of young people with autism:

- *Financial barriers* were a topic of each conversation and reflected in the survey. One survey respondent stated, “It is difficult for families who are struggling emotionally and monetarily to even consider the arts.” When therapies and treatments are often out-of-pocket expenses for families, some participants in the focus groups urged that paying even a few dollars for an art class or admission ticket can present an insurmountable challenge.

- *Geographic access* problems were identified most often in survey responses, perhaps because the roundtables were almost entirely populated by people from the three “C” urban centers in Ohio. These respondents requested that the Ohio Arts Council and VSA Ohio attend to making sure opportunities and dialogue happened in all counties of the state, urban and rural.
- *Transportation* was identified as an access problem in every roundtable session. Whether transit infrastructure is insufficient, whether schools do not have the budgets to transport children to arts and cultural programs, or whether parents’ work schedules prevent their being able to take their children to additional programs, transportation presents a pervasive access problem. One teaching artist shared that this access problem impacts families, schools, and organizations. “It’s one thing for a teaching artist to go into a school but to get those kids to come to your program after school so that it’s not a school-based thing...is so hard.” She referred to a program that has 30 buses to bring children to their facility, “which is amazing, but not all companies can have that access.”

- *Stigma and fear of stigma* was a recurring theme. Several parents and care providers identified the problem of fear of being stigmatized as “that family” prevented them from fully engaging with arts experiences. One speech pathologist who is also the mother of a boy with autism shared, “As a parent, going in to something with my children that’s arts, in the arts world, or arts-centered - having been through, you know, meltdowns, or being in the community and you’re just on edge, or you’re just ‘Oh, what’s going to happen today? Is it going to be...too loud? Is...clothes going to be okay on him?’ You know - I mean, what are they going to do?” A teaching artist suggested that the real problem lies with the parents of neuro-typical children. “It’s not the kids. The kids get it; the kids are there every day [with the kids with autism]...The parents don’t know how to deal with the one or two kids there. So it’s the parents that need the educating.”

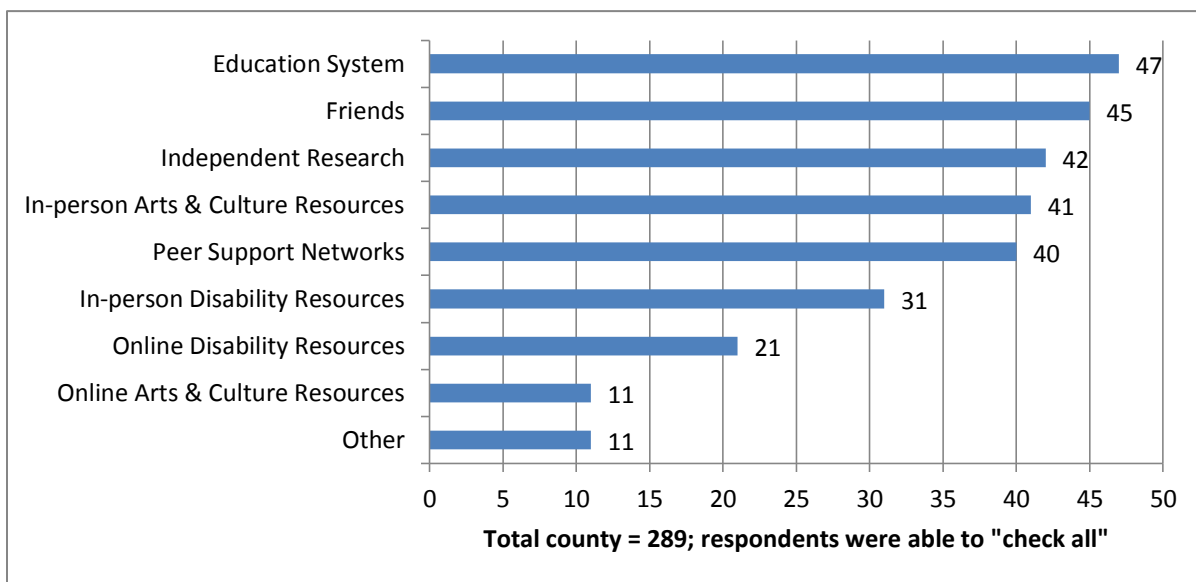


- *Lack of knowledge* - on the part of families and on the part of interventionists and care providers - was identified as a barrier to access. A music therapist working with early childhood intervention said, “Each individual that I work with has some sort of...artistic interest, and I don’t know where we can take them where we can, you know - afford, where the parents can afford it, or get the materials, or any of those kinds of things.” A family member of a person with autism who responded to the survey stated, “I could not even tell you of one program that I am aware of that is involved with the arts.” Specifically, there is a knowledge gap

around what it would look like to engage in an arts *experience* like a play or museum visit rather than an arts *participation* opportunity like a class or workshop. One of the most persistent challenges for the researchers and conversation facilitators during the roundtable sessions was in drawing out ideas for what they would like to see from arts consumption experiences for people on the spectrum. Though this situation may have many implications, two may be that, broadly, people with an investment in creating opportunities for people with autism have a challenge in seeing a way forward in this arena because they simply don't have enough knowledge to project a vision, and they are focused on their current work (funding, programming, etc.).

The Arts & Autism survey asked which support systems respondents had used to identify arts experiences for youth on the spectrum. Even the most cited response, "Education System," only garnered slightly less than 40% of respondents. This may suggest that respondents simply don't have time to seek arts experiences, don't perceive it as accessible, don't know where to look, or don't have a reason to look (as in the case of cultural administrators without children on the spectrum).

Chart #6 Support systems used to identify arts experiences.



Access barriers identified for arts organizations and individual artists:

- *Knowledge* is essential, but lacking. Several respondents, especially in the survey responses, suggested that artists and arts organizations (outside of those who serve people on the spectrum or with developmental disabilities specifically) simply did not have enough knowledge about autism as a disability, about the benefits of art experience for people with autism, about the people on the spectrum who might already be a part of their audience pool, and/or about how to

engage and manage participants on the spectrum. One autism interventionist, a behavioral specialist, recounted a story about trying to persuade some musicians in her personal network to come to work with her clients, but there was a “wall” in their minds she could not surpass. “They’re like, ‘We don’t know what to do.’...You’ve got these great people who I want to come work with...the individuals with autism but there’s that, like, what if they act up?...what if they hit that person or spit on them or something that they’re not prepared for?”

Among the ideas presented in survey results, the overwhelming preference was for different kinds of training for the general public, artists and arts educators, and arts administrators. Training must focus on how to reach, serve, and respond to challenges with children and young people on the spectrum. Some organizations represented in survey responses claim never to have had a request for supports or accommodations from a family with a member on the spectrum. Whether this is accurate, or whether barriers to participation exist which the arts organization may not recognize, the researchers cannot be sure.

- *Lack of training* was an overwhelming theme challenging the arts and autism arena. Participants in the roundtables and survey identified several areas where they, collectively, wished to see improved training opportunities around the intersections between arts and autism. These areas included: more training for art educators, training opportunities for general education teachers about the benefits of, training opportunities for arts and cultural administrators on good practices for engaging and including audience members on the spectrum, and one-off and deeper or longer-term training opportunities for teaching artists, potentially involving practicum or residency components.
- *Contact with audiences* is missing. One access problem for arts organizations is lack of contact with the networks that would give them the tools to take an active stance in seeking out audiences with autism. Additionally, the community of interventionists, educators, and care providers who specialize in autism represent another important network for arts organizations to contact. By and large, these connections are only happening in a one-off or happenstance manner. One survey respondent who provides sensory-friendly performances and inclusive workshops stated, “We are doing exciting things at my organization...and are working to continue development on the programs we offer by working with parents, speech pathologists, occupational therapists, and special educators. *However*, we have not had success in finding this audience.”

One parent of a child with autism praised the readiness of arts organizations in Columbus to serve, but noted the audience access barrier.

The arts scene in Columbus is very nonjudgmental and very inclusive, and it’s very exciting - they don’t judge the population that comes to encounter their art. Especially the grassroots - they welcome it...But what hasn’t been tapped is [the] community outreach [that brings

cultural institutions] and the parents together. But the thing in our hyper-networked world is you've got to hit it everywhere, and you've got to hit it regularly or it won't happen.

Funding is a pervasive concern. One survey respondent who advocated for the Ohio Arts Council playing a role in funding sensory-friendly programs and classes targeting children with autism noted, "funding...always seems to be a[n]...issue. Performance/arts venues rarely have the extra funds to do specialized presenting of programming that is this specific." A roundtable respondent identified the practical funding challenge inherent in creating a program like a class or workshop that serves fewer students at a time. In other words, it costs the same to offer a class for four students as it does for 20 students, but the revenue would decrease dramatically if only four students paid tuition. According to one education coordinator working for an organization with a specific mission to serve people with disabilities, they may receive funding from state or county Disabilities Services offices, but then they struggle with being committed to outcomes other than pure art-making.

Lack of empirical research supporting the impact of the arts on people with ASD. Another problem articulated by respondents at roundtables and in survey responses was a broad lack of scientifically validated or empirical research confirming the outcomes of art experience and art participation for children and young people on the spectrum. Several music therapists referred to the strategies being played out in their field to remedy this lack, citing studies on the outcomes of music engagement. One man, the founder and director of a small arts organization, proposed that the Ohio Arts Council might intervene with funding to support smaller programs that may not otherwise have access to the resources necessary.

There needs to be money going to these organizations like ours (*some laughter in the room*) that fund for us to show the outcomes. And fund for us to compete with the billion dollar education industry that is able to spend millions of dollars on data.



Though empirical research is lacking, some participants worried that the privileging of "numbers"-oriented data pushes other types of assessments to the periphery. One theatre practitioner, who is working with a large research organization aiming to scientifically validate the outcomes of her work, suggested we need to redefine what is valuable. "It'd be great if that, if it turned out to be a positive result, but if it doesn't, does that mean that our program is not of

value?" Another person, a music therapist, articulated the challenge of standardizing and generalizing results-based outcomes in a population as diversely presenting as the spectrum. "So how do you standardize...? When I'm individualizing my treatment,

how do I standardize that in a way that I can show quantitative results?” Other participants, in varying ways, communicated ambivalence about the pressure to produce or to line up with validated outcomes, as in the instance of the teaching artist who said that grant-makers no longer want to see photos in their final reports - they only want numbers. Funders must also understand the value of program outcomes through public value and personal stories.

The problems faced by young people over the age of 18 are distinct from those experienced by younger children on the spectrum. Evidence from this study suggests there are not enough experiences for children under 18, but access to arts experiences drops off radically when individuals turn 18 (or 21) and are no longer in school. One survey respondent (the family member of a person with autism) urged, “Get the word out to schools, but beyond that to those in the community who missed being diagnosed because they are older.” Though the people in our roundtables focused primarily on the problems for school-age arts participation, at least one mother of a 17-year-old daughter with autism asked the question, “What is she going to do?” for arts experiences after she turns eighteen. The implication of her question is that there is no suitable answer.

One education coordinator for an organization that serves people with developmental disabilities said that lack of consistency in services and experiences in the earlier parts of the lifespan can compound the difficulties of arts participation later.

When we’re working with adults, we find that because of a lack of history with that person as they’ve gone through their life, as they’ve transferred through differentmaybe they grew up at a time when nobody was researching anything about...their disability...maybe they passed through many staff persons - whatever the case, you know, we don’t get some packet that comes with the person that says ‘These are all the things we’ve tried.’...we go through a lot of trial and error.

She went on to suggest that when people on the spectrum gain experience with their own ways of working in an arts setting, they can become more active in asking for and communicating what they need. In other words, they become their own advocates.

Inclusive and non-inclusive opportunities present different problems. Focus groups were repeatedly probed on this topic. One option for arts organizations is to prepare instructors and design programming that is open to everyone (with and without ASD), perhaps using strategies such as Universal Design for Learning to ensure all participant needs are met. The other option is to create programs exclusively for individuals on the spectrum, separate from their typical peers. Participants provided incredibly mixed responses about their preferences. Respondents who discussed inclusive programming noted a greater urgency for the instructor or facilitator to be nimble and respond to a broader range of needs. While exclusive experiences are in some contexts more common and easier to access, they can breed isolation and present tangible financial barriers.

One young man with Asperger’s Syndrome described a frustrating experience attending the symphony with his high school, a mix of ASD and neurotypical students, which indicates the presenting organization’s lack of preparedness for different types of learners. “I just got kind of bored on all those stuff too, cause it was all just in your face, and....nothing there to explain it except for a bunch of text that you had to read and I’m not good at that.”

This paradox of inclusion versus specialized programming warrants more research. Who is claiming the benefit/outcome, and in what arena? While this research was inconclusive, it was frequently the parents of children with autism who came down firmly on one side or the other, citing pros and cons for each. In effect, some parents want their children to be included. Others perceive their child does not have the capacity to participate in programming with “typical” kids. This paradox reflects personal beliefs, the protective nature of parents, awareness of their child with ASD’s capacities, and the very real spectrum of communication/behavior/socialization which affects young people with autism. The following figure summarizes *some* of the advantages and disadvantages of the paradox of inclusion for people with autism.

	Advantages	Disadvantages
Inclusive Opportunities	<ul style="list-style-type: none"> • Socialization with “typical” peers • Feeling of belonging • Focus on art process, not disability 	<ul style="list-style-type: none"> • Lack of training by staff • Lack of sensory-friendly preparation • Challenges to individualization • Fear of stigma/behaviors
Specialized Programming	<ul style="list-style-type: none"> • Experienced/trained staff • Customized accommodations • Sustained involvement more likely • Lack of stigma 	<ul style="list-style-type: none"> • Higher costs • Reinforces difference • Focus on non-arts-based outcomes

Different organizations face distinct challenges in offering programs and connecting to audiences with autism. Challenges vary according to organizational budget and access to funding, audience capacity, working mediums, location, and marketing infrastructure. For some organizations, retaining audiences that they already have is the main priority; for others, the priority is to reduce costs; for others (especially those who offer overtly therapeutic services or who receive money from county and state boards of developmental disabilities), it is to operate according to specified outcome measures.

Systemic issues which create barriers to arts experiences and complicate individual and collective relationships to art are distinct from problems which impact individual families and organizations.

- Education system. Many roundtable and survey respondents lingered on the practical conditions in public schools which often have limited arts classes due to budget cuts. Often art classes are treated as a “dumping ground” (at least two

roundtable respondents on two different days used this language) for opportunities to mainstream special-education students,

- Healthcare system. The main relationship that these research results have to systemic issues in the healthcare system is the Interventionists relationship to art as therapy or art in general. One survey respondent argued, “The interventionists/physicians/therapists need to be convinced that this kind of sensory work is crucial to the growth of the children before they consider referring or recommending drama/visual arts/music/etc.”
- Transportation system. Transportation was identified as an access problem and also a system-wide problem that impacts people with disabilities disproportionately. Participants discussed problems specific to their city system, including an “accessible” bus service that effectively requires riders to “hurry up and wait” due to broad estimates in bus arrival time and low tolerance for missed reservations. For many people on the spectrum, this “hurry up and wait” condition is anxiety-producing and difficult to comply with.
- Perceptions of art as “luxury.” The ambivalence about art as a therapeutic or life-betterment tool is both a cultural/systemic problem and a practical one. Service providers observed that for the populations that they serve, families are often paying out-of-pocket for occupational, physical, and other therapeutic services. This means art therapies or other arts experiences often come last or not at all. Arts therapies and other arts experiences are frequently not eligible for waivers or for other kinds of governmental support. Other respondents expressed fear that, because art classes are being cut from school budgets, the arts are coming to be seen as unnecessary extras. This systemic issue has an impact for individuals with ASD, their families and caregivers; school systems; and therapists, doctors, and other interventionists.
- Awareness. The lack of awareness of autism’s prevalence and the variance that makes up the spectrum continues to be a problem. Though some participants did note that awareness is increasing. A few roundtable respondents identified the double-edged sword of “Autism Awareness.” One respondent expressed dismay that, while awareness efforts have made people more aware of the word autism and the growing incidence of autism in the population, this small shift in awareness has hidden costs. “Until they actually see and know and experience a person with autism, or multiple people with autism, they have no idea....they don’t actually understand what it is, and we get so caught up in the perception, especially of those with communication delay, of what they look like.” Connected to these broad cultural perceptions of autism are the recent changes in the diagnostic details of autism reflected in the DSM-V, which may confuse people with only incidental knowledge about the spectrum, and potential ambivalence about the legitimacy of the growing prevalence of autism diagnoses.

Solutions

Collaboration

By far, the most commonly offered solution to the problems of connecting art and autism involved collaboration. Respondents articulated a need for work to happen with not only arts and cultural administrators but with health and caregiving professionals that serve children and young people with autism. Respondents advocated for professionals and nonprofessionals working together to develop strategies, each bringing the strengths and knowledge from their respective fields.

Respondents encouraged the OAC to consider what it might look like to invite peoples' *teams* to the table (that is, the varying health, education, and care professionals that are consulted on any individual's care plan); to recognize the benefits of artists from different mediums engaging the same group of children; to make sure the artists get to talk to multiple people in the child's life; and to bring artists in as persuaders, advocates, and equal partners in the child's plan.

Several respondents offered an important nuance to the mechanics of this collaboration, anticipating a privileging of the voices of autism experts in this collaboration. Artists, they said, have an important voice in the process of identifying needs and benefits, and autism experts and policymakers have things to learn from artists and teaching artists. One participant, the father of a young person with autism, said that he would most like to see the OAC convene in-person meetings between artists or representatives of arts organizations and "decision makers," people with influence on public policy and "pots" of money.

You get people like [the teaching artists we've heard from] and all the people that run these programs to describe what they do and why they are important to this population. And...what the results have been...You sell it. Which you can all do because you've all done it already...And also you have to make sure that people, professionals in the mental health system...link up with people who provide the services who don't have administration or health degrees. Put the artists and the business people or the mental health professionals...put them together and team them up and make sure that one understands the other completely, or as completely as possible.

Some participants noted that this collaboration does not necessarily need to be initiated entirely by a statewide or broadly impactful entity like the Ohio Arts Council. For almost every individual with autism who is receiving therapeutic



treatment from caregiving professionals, the model of care they receive can serve as starting-point models for this kind of collaboration. One autism advocate and service supporter stated the model in this way: “a team approach. And I really believe that’s the best way to work. We have to look at...the child’s needs, the family’s needs - we need to be on the same page as the speech [therapist]...on the same [page] as they occupational therapist...and physical therapy in some cases.”

An administrator of a nonprofit arts organization primarily serving people with varying developmental disabilities emphasized

In order to do arts-based programming that’s non-clinical, we have to stay in really good communication with clinical providers....We’re working hand-in-hand with a network of folks...It does take a lot of different perspectives and people coming together with different roles in order to do something that can be arts-based and can acknowledge the whole person...providing artists still can’t just be doing it, from our experience over the 13 years [in our organization], can’t just be doing it on our own.

The same participant who wanted to see OAC convene meetings between artists and decision-makers noted that these kinds of convenings do not do away with the need for individualized or grassroots partnerships. “The value is that Erin [of VSA Ohio] is going to send a contact sheet later, and it’s up to the rest of us if we’ve heard something that’s interesting to us to make contact with that person and hook up.” Some participants made clear that though they saw a role for the Ohio Arts Council or VSA Ohio in helping to facilitate networking, the onus for making use of these networks was on them.

Preparation

Closely linked to collaboration is the need for preparation. This means everyone involved in an arts experience is set up for success by creating and using effective strategies and tools. Preparation is something that individuals and organizations alike can do. For an individual with autism, one mother and advocate noted the importance of “priming the person beforehand, preparing them for what they’re gonna engage in. Having them try it out and practice. Getting that feedback afterwards. That process is already built into the way we’re teaching students with autism.” Organizations also need to be prepared to productively engage audiences that include people with autism by preparing staff and even by engaging the peers of their guests on the spectrum in creating strategies that begin before the arts experiences is even underway.

Among the preparation strategies proposed in survey and roundtables were the following:

- Social Stories™¹³ and other orientation materials. Social Stories™ are tools for children with ASD and their caregivers to prepare them for the structure of a special or new experience, like an art event or going to the dentist. They take the reader through the experience from beginning to end, from the time they depart from their home or school to the time they return. Typically, Social Stories™ are customized for an organization (and often made available on their website) and can even have pictures of transport vehicles and the space itself. Among the other ideas proposed here were virtual museum tours and resource guides with “scripts” that would allow a young person and an educator or caregiver to act out the process of picking up tickets at will-call, sitting down in seats and waiting for a performance to begin, or talking about a work of art.
- Staff preparation. Participants identified the importance of preparing two categories of staff members at arts and cultural organization: the people at the top of the hierarchy who set the tone and agenda for the organization, and the front-line people who engage directly with guests such as docents, educators, and ushers.
- Peer preparation. Participants discussed the importance of preparing the peers of children and young people with autism and the other guests at an arts or cultural experience. Not only did participants suggest that peers need communications that tolerance is expected of them, but they also suggested peers can be active participants in the process of preparation itself. This can happen by finding willing peers to serve as helpers or partners to individuals on the spectrum during the art experience itself or in the lead-up.
- Family preparation. One mother of a son with autism identified herself as, by far, the most anxious participant in a preparation strategy for her son’s entrance to a new school that involved teachers, school administrators, behavioral specialists, therapists, and others. Though few specific suggestions were given about how to engage parents in preparation during the roundtables and in the surveys, comments persistently circulated around the importance of bringing parents to the table and keeping them involved in conversations.

Notably, Social Stories™ and peer training are categorized as “established” and effective evidence-based practices for treating autism by the National Autism Center in their National Standards Project.

Several participants noted that, in arts and cultural organizations, the value of preparing for success needs to happen from the top down. Without investment from dedicated organizational leaders, it is difficult or even impossible to create the conditions for effective inclusive programming. One director of an autism advocacy organization warned about the way leadership can reinforce problematic stigmatizing behavior by saying that, in the instance of schools, “if the top doesn’t get it, then it

¹³ Social Stories were developed and trademarked by Carol Gray, President of The Gray Center, www.thegraycenter.org/social-stories.

trickles down to kids who I don't believe normally would ever want to be cruel or mean to somebody else. Early on in life, that is a learned behavior.”

Notably, one of the limitations of this research sample (both in roundtables and in the survey) is that we had proportionally little participation from artists and arts/cultural educators without a pre-existing level of investment in the effort to engage more children and young people on the autism spectrum in arts experiences. If appropriate preparation is to take place, it must involve gaining buy-in from an expanding group of collaborators in the arts world.

Professional Development

This was the third most-frequently discussed solution in the roundtables and the clear front-runner for solutions in the survey responses. Professional development was identified as the most important aspect of preparation and the best way to create deeper understanding from organizations and teachers on the benefit of serving children and young people with autism.

Among the survey responses, suggestions for professional development were: a general autism awareness training; staff and artist training at organizations on strategies for serving people with autism and addressing problems that might arise; consultancies with experts at organizations like the Nisonger Center at The Ohio State University; and longer-term artist training ‘practicums’ that may include observation of varying kinds of classes. This kind of practical experience, in-class participation or observation, was identified by at least one roundtable participant (a theatre practitioner) as useful in sorting “who is very good at this and who needs to train or maybe needs to not do it. Maybe it’s not for them.” Other therapists and intervention professionals painted pictures of the negative potential of situations where training is lacking. These teachers might “end up with a table on their head in five minutes,” or are surprised to get scratched or bit by a student in a class. While extremes, these are possibilities.



Despite its popularity as a subject of conversation, the realities of professional development opportunities for general-education teachers, teaching artists, and arts/cultural administrators were slightly controversial. The special education-trained people in the room were frequently the ones making the strongest arguments for opportunities for training and professional development. Several teaching artists mentioned professional development opportunities that they heard about or even signed up for but didn't attend.

Teaching Artists, on the other hand, frequently made strong claims that, in many ways, they already have the toolsets they need to succeed in teaching and engaging kids and young people with autism. One teaching artist, for

example, urged, “I go into a classroom, there are kids with disabilities. I don’t have to be trained, necessarily. I don’t need to be trained, because it’s just the way it is. Right?” And even one of the music therapists at a roundtable session cautioned against professional development as a complete education: “Unless you’ve met that person and had that experience, you know - with autism, that personal experience - there’s just no way to teach somebody about it.”

If professional development opportunities are to be a part of the solution strategy pursued by Ohio Arts Council, there will need to be marketing and messaging around this to persuade teaching artists and cultural institution educators of its value. The benefits of professional development for educators are many, and can assist with assuring full engagement and maximum success of students with autism.

Presence in the community

Respondents proposed that artist with disabilities in general, and artists on the spectrum in specific, ought to have a more legitimate presence in the community. This presence can be part of raising awareness of successful artists with ASD. This presence in the community involves finding a venue where success stories can be told and inviting the general public to focus on the positive, not the challenges of ASD. One mother of a son with autism who also works on intervention in a medical context said, “I would like to see - who’s a successful artist [with autism] in the Columbus community, and what did they do to get to that point?” One suggestion theme that emerged in the survey was for the Ohio Arts Council to support or promote exhibitions or presentations of artwork by people with autism. An increase in public presence may be one remedy one music therapist and studio administrator’s concern that people with autism be viewed “not just as the egg shakers or the tambourine players, [but] as equal partners” in creating art.

Sensory-friendly environments for art experiences

Importantly, focus group participants did not privilege one arts medium above another as a suitable arts experience for children and young people on the spectrum. The Arts & Autism survey question about beneficial arts experiences reflected greater responses for visual arts and music, but the mix of responses was broad enough for the researchers to conclude any medium can be argued to be beneficial. Likewise, in the focus groups, respondents imagined that sensory-friendly environments for art experience are possible no matter the medium.

That said, more examples of musical environments were given than other mediums. One music therapist imagined the following.

Some kind of inclusive, flexible concert...where extra sounds are not seen as something, you know, everyone turns around and the family feels out of place. Getting up because there’s movement in the music and the person wants to move, move along, dance along with it...breaks- the timing of the program being designed so it really is

within the scope [for] people who have attention issues or people who need more breaks.

Another music therapist described an experience in a program she helps to create, which creates a sensory-friendly performance environment in a small concert space. Her observations bring together the importance of collaboration, preparation, and access to money, long-term investment.

We have children who will dance out of their seats and dance over toward the performers. The performers are ready for it because they've been prepared. They welcome this. The performers are hand-picked, in terms of people who will relate well and will be flexible. It's a beautiful thing. A variety of music. It's not just a one-shot....it can't just be a one-shot deal. The people are learning from it, and they're growing from it and progressing....And boy, if an agency would get on board and be able to, you know, hire someone and engage someone who would be able to prepare a social story...wouldn't that [be great]?

In this effort, smaller organizations might have a more prominent role to play. One administrator of an autism education organization envisioned this kind of environment being created in "kind of a smaller venue, more comfortable venue - people are not paying so much money for their seats so they're much more willing to allow for a disruption....So going smaller and then going bigger, that's nice too."

One mother of a daughter with autism who also works at an autism education organization identified another aspect of what it means to be an inclusive or sensory-friendly space: to have a broader organizational stance that actively communicates welcome for people regardless of learning style or ability.

We talk about having some separate hours which is nice for that time. But I guess the next level is, what if there isn't a special time and someone with autism or another disability is coming at another time? Well, we have no-smoking signs. We have signs that say 'no cellphones.' How about some positive signs that say, 'We are an inclusive setting, we have a variety of people here'?

She also suggested a pre-show announcement at any performance, technically "sensory-friendly" or not, that alerted guests to the presence of a variety of people with a variety of learning styles in the audience. Another participant, a music therapist, chimed in with an idea that any teachers' resource guide published by an arts or cultural organization could include information about the variety of learning styles and a statement of expectation for tolerance of difference.

Artistic Process

The last prominent solution that emerged in the focus group sessions was promoting the value of artistic process. The value of process, in contrast with the automatic privileging of a consumable art product, was threaded through all three focus group sessions. The reasons process is valuable ranged in quality. Some people suggested this is because it is valuable to engage with materials and follow a process, perhaps traveling on tangents and side-paths along the way. Others emphasized the dialogic quality of creating and interfacing with an educator or facilitator. Still others suggested that the best arts-consuming experiences might be ones that allowed children or young people with autism to see “behind the scenes” and talk to artists about their process.

In her role as facilitator, Sharon Malley asked one young man with autism who is a musician what his dream would be in regards to his music. He responded by saying, “Recording stuff. I like recording a lot more than I do performing. Recording is my - because if you record it, you get to have it. If you perform it, it’s just gone with the audience, it’s just gone into the air after you’re done.” When asked if it was important for others to hear his music, he responded,



“It’s important for me to have my music, a lot - but I’d like for other people to hear it as well. It’s not as important for other people, in my eyes, to hear my music, as much as it is for me to hear my music.” For this musician, the process, and his own encounter with his own creative output, was identified as more important than a product that he might distribute to a broader audience.

Several teaching artists or parents recounted the value of a consistent process of engagement being built in to the experience of something like a class. One parent suggested that, in her daughter’s experience, effective classes have had a “calming effect” because of the “routine and the rhythm and the like, ‘I know what I am supposed to do here.’” Another person, a teaching artist who works with theatre facilitation techniques, identified strategies that served as rhythmic anchors for the group, such as the exercise children engaged in at the top and bottom of each session.

More than one contributor noted that valuing artistic process runs contrary to the priority many funders place on tangible program outcomes. Funders want to know the duration of a program, what the measurable (or at least narratable outcomes) will be, and want to emphasize a culminating event for an arts program, a “take home.” Therefore, a solution that involves privileging the artistic process needs to be strategic.

Long-term, incremental experiences

Importantly, long-term, incremental experiences are integral to process. This emphasis is reflected in the literature that aims to identify outcomes from art experiences on young people with ASD. Many studies only identify measurable benefits and outcomes after sustained engagement in a one-on-one or group scenario. One mother of a daughter with autism who also works with an autism education organization urged the researchers that the benefits of the art experience may not show up right away to the outside eye.

I think it's important to share with the public or with the institution that it is a process for the person with autism, that the way you see them on day 1 is not going to be the end product. And so the goal isn't that individuals with autism - or anybody - behaves inappropriately. That's not the goal....in order to get them to a better behavior level, it's a process and you may see some of these bumps and bruises and - you know - the sausage-making in the back, you're going to see in the front....it's part of this process to get them to a more appropriate and inclusive way for everyone to get along.

Another participant, the administrator of an arts program that serves people with a range of disabilities, emphasized the way long-term engagement promotes trust. Conversely, unexpected shifts in care provision or program facilitation can have a negative impact. He also emphasized that adequate collaboration and preparation can prevent these kinds of problems.

It's really that kind of network of folks that are all tuned in to the same information, know who each other are so they can refer as appropriate, deal with crises as appropriate, and not feel alone to where the provider drops the ball, or ducks out of the relationship, and then you have the client or the artist kind of - there, who invested time into this new relationship and then....they're not as trusting of the arts.

The Ohio Arts Council's Role

As previously noted, focus group participants required repeated probing to think globally about the Ohio Arts Council's role in making the arts more accessible to young people with autism, but did provide several ideas. Survey respondents used the open-ended question to make numerous recommendations on the OAC's role in bringing some of these solutions to fruition.

OAC as funder of programs

Suggestions for programs included sensory-friendly performances; inclusive workshops; training opportunities for teaching artists, general-education teachers, and arts/cultural administrators; residencies (for teaching artists at organizations that

serve people on the spectrum, and for artists with autism at arts organizations); transportation initiatives; and exhibitions of work created by people on the spectrum.

OAC as funder of research

Specific suggestions about research included finding ways to help smaller organizations validate the work that they do; compiling a detailed list of arts programs for people with autism in Ohio; doing deeper work to confirm the impact of arts participation and arts experience for people on the spectrum; and supporting the ongoing efforts to validate the professional fields of music, art, and movement therapy as important treatments for young people with ASD. Additionally, several survey and roundtable respondents suggested that the Ohio Arts Council has a role in preparing literature, including a resource guide for providers of arts programming and a “white paper” or some other research-based advocacy tool for broad distribution.

OAC as trainer and trainer of trainers

Professional development and preparation were prominent solution themes. Respondents frequently positioned the Ohio Arts Council as an education engine, providing ways for teaching artists and arts/cultural organizations to learn about the individual and broader impact of the autism spectrum diagnosis, best practices for engaging an audience that includes children and young people on the spectrum, and helping to make practicum and residency opportunities available.



OAC as information repository

One idea presented in two of three focus groups was that the OAC develop a database of existing programs in Ohio which serve children or young people with autism. The database could be searched by different categories, such as inclusive/noninclusive, type of arts medium, distance from a certain zip code, duration of program, and age group served. Participants in the focus groups suggested such a database would be most effective if it was connected to the major autism advocacy and education organizations in a given area.

OAC as facilitator

Taken collectively, respondents wished to see the Ohio Arts Council play a role as a go-between in a number of different ways, and in a range of settings.

- Linking small and large organizations in order to facilitate partnerships, develop creative programming, and share ideas in order to build on the work each is already doing. Both types of institutions bring different strengths to the table for this type of work. Respondents noted that small spaces seem to enable more engagement for youth with ASD and have lower bars for access and participation due to lower price points and perceptions of what behavior is “acceptable.” Larger

institutions have the capacity to access larger pools of funding and resources. Facilitating linkages provide the opportunity to build on the work each is doing.

- Linking small organizations with funders, including but not limited to the Ohio Arts Council itself. Funding opportunities could promote partnerships between different sizes and types of cultural and community organizations, reinforcing the outcomes noted in the previous bullet point.
- Participants wished to see OAC convene networking sessions that would facilitate connections between programs, artists, and decision-makers (namely, legislators). Meetings would allow for conversations and planning taking place between parents, children with autism, advocates, and artists. Small and large organizations will also benefit from these networking opportunities.
- Bridge-building between urban and rural opportunities. Survey respondents in particular identified a lack of opportunities outside major urban areas. One cultural administrator in a rural area who was interviewed noted that the “Autism Movement” was not prominent in the area.
- Many respondents bemoaned the condition of training for public school educators, both special education and general education, and requested that OAC prioritize training opportunities for educators in the public school contexts. The primary distinction is that special educators need training in the arts and general educators need training in working with children with autism (and other special needs).
- Respondents referred to the role the Ohio Arts Council can play in facilitating communication between organizations and the broader public in a number of ways: communicating the value of the arts for people on the spectrum, telling “success stories” of people on the spectrum seeking a career in the arts, connecting members of the public with inclusive opportunities (whether they are on the spectrum or not), and promoting information to schools and families who might have older children on the spectrum.



Conclusion & Recommendations

Conclusions

The purpose of this research initiative is to inform direct programming, cultural policy, and future partnership efforts. It advances new goals identified and outlined in the Ohio Arts Council's forthcoming Strategic Plan. Further, leadership and staff at the Ohio Arts Council have already set aside funds in FY2014 (July 1, 2013 - June 30, 2014) to continue this work and begin Phase II, in some form.

Initial research overwhelmingly supports a significant level of interest for activities that increase access and inclusion in the arts for people with Autism Spectrum Disorder. Interest in the work spans fields and professions, regions, art form, and ages, and ability.

This research drew on several sources of data: a literature review, online survey, three focus groups, and several direct interviews. As noted in the Methodology section, several limitations to data collection efforts mean that conclusions should be taken into account, but more information remains to be gathered. The researchers, however, are confident that numerous themes did emerge from the data, some overwhelmingly, and mean that the conclusions and recommendations presented here do speak to the general challenges, benefits, needs, and wants of Ohio constituents.

Data collection yielded analyses grouped into four themes: benefits, problems and challenges, solutions, and the role of the Ohio Arts Council.

The benefits of bringing together arts and autism are: (a) the outcomes associated with recognizing and supporting the strengths people with ASD bring to arts-experiences; and (b) the outcomes associated with arts participation (finding a common language, quirkiness, artists as natural teachers, sensory and multi-sensory components, safe space, social experience, opportunity for rehearsal, leisure skill development, vocational training, and personal expression).

The challenges of bringing together arts and autism are varied and range from individual to systemic. They are:

- The challenges associated with the fact ASD is a spectrum;
- Access for the families and kids (financial, geographic, transportation, stigma, and lack of knowledge about opportunities);
- Access for cultural institutions (knowledge, lack of training, contact with audiences, funding, and lack of empirical research);
- Distinction between serving young people and adults;
- Inclusive versus non-inclusive opportunities; and
- Systemic issues in education, healthcare, transportation, art viewed as a luxury, and awareness.

Those who participated in the research initiative were also able to suggest solutions to the challenges of bringing the arts and autism together: collaboration, preparation, professional development, sensory-friendly environments, and a focus on the artistic process (as opposed to product).

While some encouragement was needed to get participants to think globally about the role of the Ohio Arts Council in facilitating increased access to the arts for youth with ASD, several ideas did emerge. The OAC was viewed as a funder of programs, funder of research, as trainer and trainer of trainers, as an information repository, and as facilitator. This research demonstrated a number of themes that are pertinent to any and all potential actions taken by the OAC and/or other institution which seeks to increase access to the arts for people with Autism Spectrum Disorder.

- If you've met one person with autism, you've met one person with autism. Adaptability, openness, continued exposure, patience, and a shared belief that a person with ASD has VALUE and can not only a contributor to their system of care, but is someone with inherent interest.
- It takes a TEAM to support someone with autism. From medical doctors to occupational/physical therapists to educators to siblings to parents to artists, to visitor services staff to the actual person with ASD - everyone needs to have a seat at the table in understanding what actions and settings will yield the most positive experience for everyone.
- The PROCESS of arts experiences is equally, if not more, important than the development of a final artistic product (painting, community performance, etc). While funders and cultural administrators may be used to focusing on an end-goal, for persons with ASD, it is the process of experience and repetition which fosters the positive outcomes associated with arts learning/experience.
- The concept of ACCESS, or lack of access, is a theme that is a challenge for the disability community writ large, and is no exception for those with ASD, or those who wish to serve them.
- PREPARATION is essential for both the producer and consumer of arts experiences provided to people with autism. Cultural institutions and educators must train staff in how to work with the specific nuances related to ASD. Consumers of the arts and their caregivers must adequately prepare those with ASD for new experiences and new settings. The importance of high quality training cannot be overstated.
- CONNECTION to information, opportunities, trainings, funding, service providers, networks, peers, and other stakeholders is necessary. While some institutions can facilitate these linkages, the onus will be on individual constituents to follow through on what is provided.

Recommendations

Sharon (Facilitator): How can we move to the next step in terms of being more inclusive of people with autism...in various arts experiences? What would be...a stepping stone?

Respondent (director of an autism education organization): I think you need to determine - you may want to step back and say “What’s the plan?” And I think you need to start with a particular place.

The following are recommendations for ways the Ohio Arts Council can frame Phase II of the Arts & Autism in Ohio Initiative, and beyond. The researchers, in conjunction with Ohio Arts Council staff, present these opportunities in an order that takes into account feasibility, investment, and impact. In general, and specifically when considering the complexities of meeting the needs of those with autism, deeper, longer-term programming and investments will have a more substantial impact on individuals and institutions, rather than broad swaths of change. Two categories of recommendations have been developed.

Green Recommendations can be accomplished during Phase II and over the next few years, require moderate investment, have a direct impact, and yield strong returns on investment

Blue Recommendations can be considered long-range, strategic planning goals, primarily resulting in positive policy and systemic changes

1. Continued Research

As discussed in the methodology section and throughout this report, there were limitations to the data collected which make it problematic to draw concrete conclusions. There is a need to continue gathering information from Ohio constituents about their perceptions, needs, and ideas for how the OAC can better support children and youth with ASD. Specifically, more data should be gathered from individuals with ASD, siblings of those with ASD, the health profession, autism advocacy groups, cultural administrators (with and without exposure to services for people with ASD), and geographic areas beyond the three major urban centers in Ohio. The researchers recommend additional focus groups in rural/suburban areas and another (online) survey with questions refined from the Phase 1 survey, distributed to additional listservs, and open for a longer time to increase response rates.

2. Task Force Development & Convenings

It takes a team to support a young person with autism; it will take a team to increase access to the arts for young people with autism. The researchers recommend creating an Arts & Autism in Ohio Task Force which is charged with accomplishing future phases of this work and achieving goals set forth in the OAC's strategic plan. Ideally, the group will be comprised of diverse individuals (fields, ages, power, etc.) who are linked by the Task Force's mission, and led by an individual with time to devote to the work, knowledge about the fields of art and autism, and sufficient investment/obligation which ensures the work is completed in a timely fashion.

Time and again, research participants cited the need to continue the conversation. Not only does the conversation need to continue, but it needs to be broadened in scope of outcomes and in types of participants. In addition to those types of individuals convened during these focus groups, more health care practitioners, educators, and legislators/

stakeholders need to be invited. The OAC has a history of convening Listening Tours around the state, and these could be considered a model for the recommended convenings. These should most certainly take place in diverse locations across Ohio and could be held 3 - 4 times per year. These would also be fortuitous times to highlight talented artists with ASD or host trainings.



3. Data Collection & Resource Development

This recommendation includes several distinct options.

- a. Engage a consultant to create a searchable database of opportunities/resources for the arts and autism in Ohio. This individual should collect as much information as possible on accessible arts experiences in Ohio, cultural institutions which offer the experiences, statistics about each experience (cost, location, non/inclusive), resources for parents/cultural administrators/educators, and others. Beyond cultural areas, the health system, education system, and autism advocacy world should be explored as places where these opportunities exist. A media campaign could be useful in letting statewide audiences know it is under development and how opportunities can be sent in and added to the database. This information would be maintained in a newly developed online, searchable database. Importantly,

a system or staff member will need to be assigned responsibility for maintenance. Based on input from roundtables, the success of such a venture would be in ensuring it gets exposure and backing from autism advocacy and education organizations around the state (ie. Ohio Center for Autism and Low Incidence), as these often serve as the first point of contact for a family with a child on the spectrum and who often are not connected to arts opportunities in their area.

- b. Develop a Toolkit of Best Practices for Cultural Institutions. This may be best done in collaboration with experts in the field of autism or national experts in accessibility such as The Kennedy Center. The Toolkit should be made available online and available for download as a free PDF to maximize usage. If funding is available, the OAC may consider printing a limited number of copies that are distributed to grantees and other stakeholders.
- c. Support the development of a print Toolkit of Opportunities for families which is modeled after the data collected for the online database. This could mean a larger publication with many of the details and opportunities available in the database, or a pamphlet with highlights and information on where it can be found online. Distribution should be targeted to health systems, education sites, and autism advocacy groups. This Toolkit may be something that is developed beyond Phase II, after the database has been developed and more information collected from additional research.
- d. Support the development of an Educator Resource Guide which would provide best practices on working with people with ASD in the arts, creating Universal Design for Learning lesson plans, or quick and easy programs that parents may be able to use at home with their children.

4. Grant-making Opportunities

Funding for arts experiences was one of the greatest needs and barriers to access cited by both art consumers and producers. Direct costs include transportation, tuition, wages, and operations. In addition to the funding required to implement some, or all, of these recommendations, the OAC should consider finding ways to decrease financial barriers. The OAC may wish to review its current grant opportunities that can be amended to prioritize programming in cultural institutions for young people with autism, free tuitions for qualified youth, conduct the proposed research outlined here, or fund trainings which better prepare educators, docents, artists, and teaching artists to create programs and/or work with people with ASD. Potential current grant categories where this may be a natural fit include Project Support, Building Cultural Diversity, Arts Partnership, and Artists in Residence.

Note: Due to the nature of ASD, grants may be more impactful when they support efforts which plan for long-term programming and/or smaller group engagement. Further, participants noted that smaller spaces and institutions have been more successful at being accessible and flexible, and navigating less bureaucracy. This does not mean large institutions cannot create similar programming. However, the researchers have found that cultural institutions offer accessible programming either because of a passionate individual, or because it is built into the mission of an institution and leadership makes accessibility a priority.

5. Professional Development

This is an area of the utmost importance to successfully increasing access to the arts for young people with autism, and was repeated again and again by research participants. Tailored trainings can benefit artists, teaching artists, general educators, arts educators, cultural administrators, docents, volunteers, parents/siblings/caregivers, occupational/physical therapists, and other stakeholders. For example, teaching artists and arts educators need training on how to manage behaviors and cultural administrators/educators need training on how to modify/develop institutional specific programming and operations which meet the accessibility needs of the intended audience (ie. sensory friendly programming). Professional development may take the form of workshops, webinars, model performances and/or residencies, mentorships, and/or long term trainings which end in certification.



Before engaging in broad professional development offerings, it will be important for the OAC to contract an expert/s to guide professional development sessions. The expert/s may be from Ohio or from a nationwide search, but they must have a resume which qualifies them to train trainers in Ohio. This initial investment in building Ohio's human capital will ensure adequate supply of trainers to meet demands, and enhance statewide capacities.

Participants also need to understand the complexities of working with children with ASD and the value of attending trainings. While artists may be ahead of the curve of educators in terms of flexibility, quirkiness, and expectations things may not go according to plan, it is essential that they recognize young people with autism are not just another quirky kid. Respecting them the same as their typical peers is important, but children with autism deal with a disability that requires unique approaches and treatments. Further, the best educators are ones who believe they can always learn something new and this training will only make their teachings better.

6. Advocacy

Results from this and future research and efforts need to be broadly disseminated to cultural institutions, the public, autism groups/support networks the health industry, educators, legislators, and other stakeholders. The OAC's Public Information Office must work with researchers and, potentially, the Arts & Autism Transition Task Force, to develop a media plan which reaches not only all corners of Ohio, but nationwide audiences. The media is wrought with stories about autism and it is currently a "hot topic" for many fields. Building on this existing interest and an open public policy window, a strong, clear message has the potential to create systemic change. Two types of advocacy can be considered:

Micro Advocacy - Increase outreach and awareness efforts about this Initiative and the OAC's strategic goals directly to cultural institutions and audiences. This can be accomplished through coordinated efforts in both the OAC's Public Information Office and Grants Department. Encouraging cultural groups to prioritize and promote access efforts should include information about the benefits, challenges, basic needs, and how to find audiences which use access services.

Macro Advocacy to Legislators, parallel fields, stakeholders, and the general public. The messages of "arts and autism" and "arts for all" should continue to be part of the OAC's outreach themes. Data that becomes known from additional Initiative efforts (ie. public value stories, research results, unique partnerships) can be used to further advocacy efforts.

In addition to promoting this Arts & Autism Research Initiative, agenda and ensuing efforts, the OAC may have a hand in advocating for professional artists with ASD who have "made it" and inspire others to pursue the same. These subjects would be better highlighted if their stories of disability were only part of their larger stories. The goals of such an effort should be to convey talent, promote tolerance of difference, and create role models, not a "token" person with a disability. For example, the ReelAbilities Cincinnati Disabilities Film Festival theme in 2012 was "Different, Like You," and featured posters and stories about people with disabilities, some of which were visible, and others that weren't. The *DiverseAbility Ohio* 2012-13 magazine published by Wright Choice, Inc. is also an excellent model.

The OAC should be sure to include information about *what* it does and *how* it does so in all advocacy efforts. Focus groups participants were not all readily able to articulate what or how the OAC could assist these efforts, which indicates some lack of understanding and recognition about OAC capacity. One local success story is The Columbus Foundation's efforts to position itself as a *community* foundation, an advocate for Columbus/central Ohio, and a medium for civic engagement. The OAC may research the creation of a comparable messaging effort that focuses on access and art for *all*.

7. Empirical Research

Much empirical research has been conducted on the value of the arts and arts education. What is missing from this arena is a body of empirical research on the value of the arts for people of all ages with disabilities, including autism. The music therapy field has made strides in conducting research and identifying proven outcomes for people with ASD who engage in music therapy. However, as noted, they are generally connected to human development and treatments of care. One area that may be ripe for research, as some formative work has begun, is to research the effect and outcomes for sensory-friendly performances.

Roundtable participants noted, and the researchers empathized, funders and stakeholders increasingly require numbers and data that support the value of the arts and arts education. Making the case for support has been achieved anecdotally, ad hoc, and qualitatively. However, as the OAC knows from Creative Industry and Ohio's State of the Arts reports, scientific research holds greater sway with stakeholders. The report has also noted the challenge of a scientific study that requires generalization when Autism Spectrum Disorder is such an individual condition. However, the researchers believe investment in this study would not only benefit Ohioans, but have a ripple effect to communities across the nation.

8. Arts & Autism Residency Program

As noted in the Grant-making Opportunities and Professional Development sections, the Ohio Arts Council may consider developing, or funding, an Arts & Autism Residency Program. This is a potential pathway for the kind of deep investment that can make a significant impact. One potential pathway for this kind of deep investment would be to choose strategic partner organizations in one or more of the major cities in Columbus, an arts partner and an advocacy/education/research partner. These partners could serve as pilot locations for programming in a number of the arenas of interest addressed in round tables and in the survey, including but not limited to:

- a. Identifying teaching artists and artists with autism for residencies at the artist partner organization or other organizations
- b. Pilot programs that serve an inclusive audience that may include a research component and a practicum component
- c. Sensory-friendly environments for performance or other arts experience built into the regular season or program calendar
- d. Development of template preparation materials like Social Stories™ and a resource guide for administrators and teaching artists
- e. Studying ways that arts practices overlap with established, evidence-based practices laid out in a document such as the National Standards Project developed by the National Autism Center.

- f. Development of networking opportunities that include the voices of children and young people with autism and their families, arts/cultural administrators, artists, autism advocacy and education professionals, and autism interventionists and caregivers
- g. Professional development opportunities for teaching artists, administrators, front-line people (docents, ushers, box office workers)
- h. Vocational training for young people with ASD at cultural organizations

9. *Collaboration with Education & Health Fields*

This recommendation should be considered a long-term action item, with the goal of creating systemic change. The Ohio Arts Council will need to review their spheres of influence and support high-level engagement (ie. Director of the OAC) which connects the OAC with different fields. Areas for consideration in these collaboration efforts include state agencies such as the Ohio Department of Health, Ohio Department of Education, Ohio Department of Family and Children First, Ohio Rehabilitation Services Commission, and Governor’s Council for People with Disabilities (part of Ohio Developmental Disabilities Council).

The thrust of such efforts would be to convey the value and natural positive outcomes when Ohioans engage in the arts, the need for highly-trained professionals, career opportunities, and the need to decrease transportation/access barriers to arts experiences. These state agencies have been cited because these are the lenses through which Ohioans with autism and their support networks view their world of opportunity. Health and education are the two primary concerns when a family receives an ASD diagnosis. For the Ohio Arts Council to create systemic change, parallel state, county, local agencies will need to understand the value of integrating time, space, and resources for the arts in the lives of people living with Autism Spectrum Disorder, and any other disability.

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These recommendations represent only a few of the spectrum of opportunity available to the Ohio Arts Council. The administration of arts and cultural opportunities inherently reflect creativity and reinvention and relevance. Without a doubt, the answer to how the Ohio Arts Council can better support students and young people with Autism Spectrum Disorder will reflect those same traits. The Ohio Arts Council has a strong opportunity to position itself as a leader and partner in realm of arts and autism.

Appendix 1. Online Constituent Survey

Ohio Constituent Survey: Arts + Autism

A recent report by the Centers for Disease Control finds that 1 in 50 young people have autism. The impact of an autism diagnosis in a child results in myriad implications for parents: learning about practical ways to support development, becoming an advocate for equal education opportunities, understanding healthcare policy to secure medical needs, and interpersonal relationship building, among others.

Institutions and individuals are increasingly calling for a national discussion of diagnosis and support systems. The Ohio Arts Council is one of those institutions. As the state agency funding and supporting quality arts experiences, their vision is to provide leadership and a voice for the arts to transform people and communities. Research and anecdotal data demonstrate that involvement in the arts can make a significant difference in the life of an individual with Autism. The Ohio Arts Council is committed to accessibility and cultural participation, particularly for underserved people and people with disabilities.

Recognizing societal trends, and in response to a growing numbers of inquiries, the Ohio Arts Council has engaged VSA Ohio to explore the intersection of arts and Autism in Ohio.

The goal of this research initiative is to begin to understand how the Ohio Arts Council can better support children and young people with Autism Spectrum Disorder.

*****If you are a part of one of the round table discussions taking place June 5, 6, or 7, please do not take the survey. Our research protocol requires in-depth, unrehearsed discussions, and we prefer that you do not anticipate discussion questions.**

1. How do you identify yourself? CHECK ALL THAT APPLY

- Individual with Autism
- Family member of person with Autism
- Special Educator
- General Educator
- Arts Educator
- Education Administrator
- Teaching Artist
- Music Therapist
- Disability Service Provider
- Medical Professional
- Arts/Culture Administrator
- Advocate
- Other _____

2. Please select all descriptors that apply.

- I am on the Autism Spectrum
- I am a parent of a child on the Autism Spectrum
- I am the family member of a person on the Autism Spectrum
- I know children and/or adults on the Autism Spectrum who I see regularly through work or social settings.

3. Describe your level of knowledge about Autism, in general.

Open Ended Box - 50 words Max

4. Describe your experience in using the arts to serve people on the Autism Spectrum.

Open Ended Box - 50 words Max

5. What kinds of arts experiences have you seen a child or young person on the Autism Spectrum engage with and gain a positive outcome? CHECK ALL THAT APPLY.

- Participating in a music class
- Participating in a visual art class
- Participating in a craft-making lesson
- Participating in a movement or dance class
- Participating in a theatre class
- Attending an arts performance (music, theatre, or dance)
- Attending another arts or culture experience (a museum, an arts festival, etc)
- None of the above
- Other (please specify):

6. What BENEFITS have you observed individuals on the Autism Spectrum gain from participating in the arts? CHECK ALL THAT APPLY

- Increased social skills
- Increased communication skills
- Increased creativity
- Increased focus
- Connection to a social network
- Increased happiness
- Other. Describe _____

7. What CHALLENGES have you observed individuals on the Autism Spectrum experience when participating in the arts? CHECK ALL THAT APPLY

- Professionals did not know how to work with/help a person on the Autism Spectrum
- Other participants (peers) did not know how to interact person on the Autism Spectrum
- Insufficient pedagogical structures (instructional approaches) in the creative environment
- Lack of interest
- Sensory overload
- Regressive/troublesome behavior
- Increased frustration
- Other. Describe _____

8. What types of support systems have you utilized to facilitate arts experiences for individuals on the Autism Spectrum? CHECK ALL THAT APPLY

- Friends
- Peer Support Networks
- Online Arts and Culture resources
- In-person Arts and Culture resources
- Online Disability resources
- In-person Disability resources
- Education system
- Independent research
- Other. Describe _____

9. What are the primary barriers to providing arts experiences for a person on the Autism Spectrum?

- Lack of access to information
- Professionals lack the knowledge/experience of how to work with people with Autism.
- Lack of opportunities that meet specific needs of people with Autism
- Financial barriers to accessing services
- Concern about interacting with other arts participants who are not on the Autism Spectrum
- Geographic barriers to accessing services
- Lack of relationship/knowledge of arts and culture organizations
- Other. Describe _____

10. What kinds of systems, trainings, information, resources, etc. would make the Arts more accessible for people on the Autism Spectrum?

open ended box - 100 words max

11. How can the Ohio Arts Council and VSA Ohio support increased access to the arts for people on the Autism Spectrum?

Open ended box - 80 words max

12. Please share any additional thoughts you have about the Arts and Autism.

open ended box - 80 words max

Thank you!

Appendix 2. Focus Group Participant Descriptions

Cincinnati

- Young person with ASD, musician
- Outreach Director, cultural institution
- Dancer/Educator/Teaching Artist
- Education Director, cultural institution
- Executive Director, cultural institution
- Executive Director/Music Therapist, performing arts institution

Cleveland

- Director of Autism research center at a university
- Artist with ASD
- Executive Director of Autism advocacy group and parent of child with ASD
- Board Certified Music Therapist
- Elementary school educator and parent of child with ASD
- Assistant Director, Department of Music Therapy, community music school
- OAC artist/musician
- Dancer/Educator/Teaching Artist
- Advocate with ASD

Columbus

- Transition Coordinator with public school
- Music Therapy Supervisor and Intern Director and school for those with Autism and other developmental disabilities
- Autism Treatment Network Site Coordinator with local hospital
- Creative Director of theater group for developmental disability community
- Behavioral Consultant
- University Theater Professor
- Parent of young person with Aspergers and radio personality
- Executive Director, cultural institution
- Executive Director, cultural institution
- Education Specialist at learning center for those with special needs

Appendix 3. Bibliography of Pertinent Literature

Art and Autism - General

Arezzini, Lynn. "Music: A Window into the World of Autism." *Journal of the American Suzuki Association*. 40:3. May 1 2012.

A mother's story of engaging with her son through playing music together.

Baron-Cohen et al. "Can Emotion Recognition Be Taught to Children with Autism Spectrum Conditions?" *Philosophical Transactions: Biological Sciences*. 364:1535. 3567-74. Dec 12 2009.

Authors studied whether one aspect of "cognitive empathy," the ability to recognize patterns of emotion signaling on human faces, can be taught to children with Autism by creating an entertainment/education DVD series called *Transporters* and showing it to children. Results suggest that improvement is possible, and parents suggested that their children became "more willing to discuss emotions and became more interested in facial expressions."

Berube, Clair T. "Autism and the Artistic Imagination: The Link Between Visual Thinking and Intelligence." *TEACHING Exceptional Children Plus*. 3:5. May 2007.

Focuses on the possibility that people with ASD bring a strength rather than a deficit to art-making, using Gardner's Theory of Multiple Intelligences as framing and Dr Temple Grandin's life as evidence.

Graham, Gordon. "Music and Autism." *Journal of Aesthetic Education*. 35:2. 39-47. 2001.

Challenges the presumption that music is only useful if it assists people with Autism in "personal expression" or emotional communication. "To depersonalize music is not...to rob it of any therapeutic power."

Grandin, Temple. "How Does Visual Thinking Work in the Mind of a Person with Autism? A Personal Account." *Philosophical Transactions: Biological Sciences*. 364: 1522. 1437-42. May 27 2009.

Grandin describes her own brain processes which she suggests are like an internet search engine and notes that "all my thinking is bottom-up instead of top-down. I find lots of little details and put them together to form concepts and theories."

Happe, Francisca and Vital, Pedro. "What Aspects of Autism Predispose to Talent?"

Philosophical Transactions: Biological Sciences. 364:1522. 1369-75. May 27 2009.

Explores different cognitive explanations (such as cortical reorganization, weak central coherence, executive dysfunction, mind-blindness, and exemplar-based memory) to move toward explaining the 1 in 10 people with Autism who seem to have exceptional skill in a particular arena like music or visual art. One useful statement: in ASC "there may be no default bias toward global processing - hence no 'talent-suppressing' top-down influences."

Mullen, Jill. *Drawing Autism*. New York: Mark Batty Publisher, 2012.

Features the artwork of 50 artists with Autism with the aim of showcasing "an array of unique perspectives on how these individuals see the world and their place in it."

Ohio Center for Autism and Low Incidence (2009), *Ohio's Parent Guide to Autism Spectrum Disorders, 2nd Edition, Developed by Ohio parents, for Ohio parents*, Ohio Department of Education. Available at www.ocali.org/up_doc/Ohio_Parent_Guide_to_ASD.pdf.

Schleien, Stuart J. et al. "Participation of Children with Autism and Nondisabled Peers in a Cooperatively Structured Community Art Program." *Journal of Autism and Developmental Disorders*. 25:4. 1995.

An older study on an experiment in creating an inclusive classroom context in a museum, focused on studying interactions between children with Autism and their neurotypical peers. Conclusions included the helpfulness of preparing neurotypical students to encourage and include their peers with ASD in cooperative behavior.

Simpson, Kate and Keen, Deb. "Music interventions for children with Autism: Narrative review of the literature." *Journal of Autism and Developmental Disorders*. 41:11. 1507-14. 2011.

Focuses on 20 studies that support the use of music to help children with Autism in the areas of communication, social, and behavioral skills.

Tools and strategies for engaging children/young people with Autism in a classroom setting

Adamek, Mary. "Meeting Special Needs in Music Class." *Music Educators Journal*. 87:4. 23-6. January 2001.

Focuses on useful strategies for underprepared/undertrained music educators, including ways to achieve the goals of partial participation, interdependence, normalization, and individuality. Particularly of note is the emphasis on quality instruments or accommodations and the four part "Student Information at a Glance" form which can be a collaboration tool and helps teachers identify strengths, weaknesses, IEP details, and tried-and-true strategies.

Darrow, Alice A. "Adapting for Students with Autism." *General Music Today*. 22. 24-26. January 2009.

Makes suggestions for the music classroom, including predictability and structure, peer modeling, partial participation, visuals, limiting choice to start. Promotes the possibility that children with ASD have special music skill and their aptitude "can be use in the music classroom to highlight their abilities rather than the disability."

Furniss, G. J. "Art Lessons for a Young Artist with Asperger Syndrome." *Art Education*. 62:3. 18-23. May 2009.

Describes a one-on-one interaction with a young artist and engages behavior modification techniques, skill development with materials. Identified benefits include interpersonal and social communication skill increases, alongside an exhibition of his work.

Furniss, G.J. "Practical considerations for teaching artists with Autism." *Schoolarts: The Art Education Magazine for Teachers*. 106:9, 6. 2007.

Emphasizes the importance of individual engagement and the value of referencing people with previous experience with an individual. References Temple Grandin's book *Thinking in Pictures* to argue for the importance of routines like sitting in the same seat and to bring forward the possibility that people on the spectrum may be more likely to choose objects as subject matter.

Greher, Gena R. et al. "SoundScape: An Interdisciplinary Music Intervention for Adolescents and Young Adults on the Autism Spectrum." *International Journal of Education and the Arts*. 11:9. August 2010.

Outlines data collected from a pilot community-based outreach program that brought together young adults with ASD and university departments of psychology and music, and aimed at developing generalizable strategies for working with people in groups outside the confines of a school.

Hammel, Alice. "Inclusion Strategies that Work." *Music Educators Journal*. 90:5. 33-7. May 2004.

Focuses on preparation strategies for music teachers that involve collaboration with students, their peers, and special education faculty that will allow students with disabilities to participate in the "least restrictive environment" possible. Especially of note is a list of possible adaptations.

Hourigan, Ryan and Hourigan, Amy. "Teaching Music to Children with Autism: Understandings and Perspectives." *Music Educators Journal*. 96:1. 40-5. September 2009.

Particular attention is paid here to helping children with Autism manage the stresses of transition, the loud room, and other environmental factors that might trigger them. Useful model provided of the "Picture Exchange Communication System" to manage transitions.

Levett Gerber, Beverly and Kellman, Julia (eds). *Understanding Students with Autism Through Art*. Reston VA: National Art Education Association. 2010.

A book-length volume that details up-to-date information about the diagnostic criteria, background/preparatory information about Autism, strategies for managing the classroom and collaborating with other educators. Also particularly of note are the "community programs" chapters which focus on experiences outside the classroom (like in museums).

Maclean, Jan. "The Art of Inclusion." *Canadian Review of Art Education: Research and Issues*. 35. 75-98. 2008.

Follows a qualitative analysis of a long-term engagement with a group of special-education secondary-education students including students with ASD called "The Story Project." Claims cognitive benefits for individuals with Autism such as active attending, increasing tolerance for ambiguity, keeping multiple ideas in the air at once, gaining a sense of agency, cultivating empathy, and focusing on symbolic forms; places value not only on including students into mainstream spaces but also "exchanging and sharing unique perspectives and approaches." Art "could offer students who struggle with learning logic and linguistics an alternative form of language."

Reynolds, Mishawn K. *A Complete Guide to Teaching Art to Those with Autism: Understanding the Elements and Principles of Design and Life Skills*. Bloomington, IN: AuthorHouse, 2011.

A resource guide on the basics of Autism, the history of and rationales for engaging people with ASD in art-making, and strategies and lesson plans.

News, popular media, and human interest

Art of Autism. Website.

A “social entrepreneurship project” focused on promoting artists with Autism and educating people about Autism.

Bronski, Peter. “The Growing Autism Advocacy of Zoe Gross.” *Vassar Newsletter*. 108:3, Fall 2012.

Zoe Gross has Autism and runs a blog titled *Illusion of Competence*. This blog entry tells some of her story, including the flow chart she uses to be sure she gets to class each day dressed, clean, and ready for the day.

Delma-Glass, Emmanuelle. “Painting the World with a Rainbow.” *The Folk Art Messenger*. 17:2. 4-7. Fall/Winter 2004.

Focuses on the artwork of Jessica Park and on her life story, as she has gone from a young child who didn’t speak and who seemed to live in a place her parents called “Nirvana” to a grown woman with a body of artwork.

Diament, Michelle. “In First, Sesame Street Goes Sensory Friendly.” *Disability Scoop Blog*. February 6, 2013.

Sesame Street Live “Elmo Makes Music” is the first attempt by the organization to offer performances with sensory-friendly tactics: prepared ushers, adjusted lighting, quiet areas, extra space in seating areas.

Estep, Erica. “Art Therapy Provides Educational Breakthrough for Autistic Students.” *6 News Blog*. July 12, 2012.

A group of children with ASD share stories about art-making in the lead-up to an exhibition of their work.

Gaidos, Susan and Wolinsky, Cary. “More Than a Feeling: Emotionally Evocative, Yes, But Music Goes Much Deeper.” *Science News*. 178:4. 24-9. August 14, 2010.

Discusses recent research on music’s impact on the brain and on how children with Autism process emotion, linking the two by proposing that children with ASD’s response to music may give us insight into how their brains operate. “While these kids often have difficulty recognizing how others feel, they readily respond to the sentiments of a song,” and “It seems like music acts as a sort of in, or doorway, to the [emotional] recognition system of children with Autism.”

Gates, Sara. “Luis Paredes, 11-Year-Old Artist with Autism, Debuts Work at National Art Exhibition.” *The Huffington Post*. August 18 2012.

Paredes won a competition sponsored by VSA National to create artwork about “What Inspires You.”

Harmon, Amy. “The Autism Wars.” *The New York Times*. April 7, 2012.

Discusses challenges of “Autism awareness” and communicating about the spectrum of challenges in the aftermath of CDC prevalence updates.

Rippe, Emily. “Second Annual Art & Autism.” *Toledo.com*. August 28 2012.

Describes an event that came about as a collaboration between a hospital and the local art commission, with support from the business community.

Thorne-Nottingham, Emma. "Kids With Autism Mimic 'More Efficiently.'" *Futurity Blog*. April 8 2013.

Cites new research from the University of Nottingham which finds that children with Autism are less likely to copy unnecessary actions (a social behavior) than neurotypical children when learning a task through modeling.

Music Therapy

American Music Therapy Association. "Autism Spectrum Disorders: Music Therapy Research and Evidence-Based Practice Support." 2010.

Essay that summarizes existing resource and overall serves as a rationale for the value of music experiences for children with Autism and the usefulness of music therapy for engendering non arts-centered outcomes such as increased attention, decreased agitation, decreased self-stimulation, and improved verbal skills.

Autism Resource Foundation. "Treatments for Autism - Music Therapy."

Summarizes arguments for the effectiveness of music therapy as a treatment option, presents a brief summary of research, and connects parents with the American Music Therapy Association.

Kern, Petra and Humpal, Marcia (eds). *Early Childhood Music Therapy and Autism Spectrum Disorders: Developing Potential in Young Children and their Families*. London and Philadelphia: Jessica Kingsley Publishers. 2012.

A collection of essays that aim to bring together evidence for the effectiveness of music therapy interventions with young children on the spectrum, alongside strategies for engaging therapists and parents together in treatment. Particularly of note are the chapters that strategize overlaps between other evidence-based therapeutic practices and chapters on collaboration between music therapists and their parents.

Other Therapies, Including Art Therapy, Movement Therapy, and Theatre

American Art Therapy Association. "Autism Toolkit." 2012.

Many links to model art therapy programs, information on art therapy training, and contact databases for art therapists. Focuses on quotes promoting the strength of art experience for children with Autism such as this quote from Dr Laura JJ Dessauer: "The creative process of art-making allows for a child to move into the psychosocial stage of industry vs inferiority. During this period, a child with ASD can use the creative process to enhance competency..."

Emery, Melinda J. "Art Therapy as an Intervention for Autism." *Art Therapy: Journal of the American Art Therapy Association*. 21:3, 143-7. 2004.

Key observations include the criticality of parent involvement and consistent, one-on-one caregiving in identifying effective treatment strategies, the relation between Autism and difficulty with forming schema, and the importance of process. Concludes that nonverbal expression through the arts can help children with Autism develop their sense of self by representing experiences over time.

Evans, Kathy and Dubowski, J.K. *Art Therapy with Children on the Autistic Spectrum: Beyond Words*. London: Jessica Kingsley Publishers. 2001.

Book-length text that explores the outcomes of art therapy treatments for children with ASD. Main suggestion is that art-making with a therapist alleviates “tension” and negative behaviors. Presented with the presumption that these therapies will be incorporated into other therapeutic practices.

Gray, Carol, “Social Stories” www.thegraycenter.org/social-stories. A Social Story™ describes a situation, skill or concept in terms of relevant social cues, perspectives, and common responses in a specifically defined style and format. The goal is to share accurate social information in a patient and reassuring manner that is easily understood by its audience.

Hartshorn, Kristin et al. “Creative Movement Therapy Benefits Children with Autism.” *Early Childhood Development and Care*. 166:1. 2001.

Findings include increased ability to stay on-task, less sensitivity to being touched, less wandering, and less time resisting the teacher.

Martin, Nicole. “Art Therapy and Autism: Overview and Recommendations.” *Art Therapy: Journal of the American Art Therapy Association*. 24:4, 187-90. 2009.

Identifies the contemporary approaches utilizing art practices (engaged by artists and non-artists alike), problems (including the scarcity of research and disconnect between art therapy and Autism advocacy and education organizations), and advantages of arts therapies. Arrives at the conclusion that more in-depth knowledge is required, beyond “anecdotal case studies.”

Nisonger Center. “Shakespeare and Autism.” 2013. Web.

Outlines pilot study and partnership between the Nisonger Center, the OSU Department of Theatre and Dance, and the Royal Shakespeare Company in Great Britain to test the efficacy of the Hunter Heartbeat Method, a set of tactics using Shakespeare’s plays and characters to engage children with Autism and improve core symptoms of ASD (especially communication and social skills). At writing research and analysis is still underway. Website features video and links.

Renino, Christopher. “‘Who’s There?’: Shakespeare and the Dragon of Autism.” *The English Journal*. 99:1. 50-5. September 2009.

An English professor’s account of engaging two teenaged boys with Autism in a dialogue about Shakespeare’s drama.

Tactics, Strategies, and Rationales for Sensory-Friendly Environments

Boyle, Katherine. “Kennedy Center Offers Sensory-Friendly Concerts for Children with Special Needs.” *Washington Post*. January 8, 2013.

Identifies some of the tactics employed by the Kennedy Center (such as vetted music, half-empty seats to allow children to move, and trained ushers) and notes that “the concert hall is arguably one of the most restrictive spaces in American culture.”

The Kennedy Center (Spring 2013), *Sensory Friendly Programming for People with Social & Cognitive Disabilities: A Guide for Performing Arts Settings*. Available at www.kennedy-center.org/accessibility/education/lead/SensoryGuidebook.pdf.

Theatre Development Fund. "Autism Theatre Initiative."

Describes efforts to make theatre in New York accessible for children with Autism and their families. Three productions have been made Autism-friendly so far. TDF subsidizes ticket costs for families. The webpage features three social stories, the list of accommodations (including light adjustments, a quiet area, and a staffed activity area) and lists of other theatre organizations who have made steps to create sensory-friendly performances.

Appendix 4. Resources in Ohio

All About Autism Event
boydstire.com/blog/view/all-about-Autism-event-is-back

Autism Internet Modules
Autisminternetmodules.org

The Autism Puzzle
www.wcmhblogs.com/Autism/contact

Autism Society of Greater Cincinnati
www.Autismcincy.org

Autism Society of Northwest Ohio
asno.org

Autism Society of Ohio
Autismohio.org

Childhood League Center - Columbus
childhoodleague.org

Cincinnati Center for Autism
cincinnatiCenterforAutism.com

Embracing Autism
embracing-Autism.net

Families with ASD
familieswithasd@yahoo.com

Great Lakes Collaborative for Autism
greatlakesAutism.org/about/contact-us/

Haughland Learning Center
www.hauglandlearningcenter.com

Helping Hands Center for Special Needs
helpinghandscenter.com

Hope Academy for Autism
hopeacademyforAutism.com/curriculum

Interagency Work on Autism
iwg-Autism.org

Knapp Center for Childhood Development
knappcenter.org

The Lettuce Work Foundation
lettucework.org

Lil Mac Kids Foundation
www.lilmackkids.org

Milestones Autism Organization
milestones.org

Monarch Boarding Academy
monarchcenterforAutism.org

Nationwide Children's Hospital Autism Academy, nationwidechildrens.org

Nisonger Center at Ohio State University
nisonger.osu.edu/asd

Northeast Ohio Autism Group
northeastohioAutismgroup.org

Oakstone Academy and Children's Center for Developmental Enrichment
ccde.org

Ohio Center for Autism and Low Incidence
www.ocali.org

Rich Center for Autism
web.yzu.edu/richcenter/

Toledo Children's Hospital Foundation
artandAutism.org/home.html

Wingspan Care Group
wingspancg.org

Appendix 5. About OAC and VSAO

About the Ohio Arts Council

The Ohio Arts Council (OAC) was created in 1965 to "foster and encourage the development of the arts and assist the preservation of Ohio's cultural heritage." This is accomplished by the Council in two primary methods; first, through the various grant funding programs that the Council operates to provide support to artists and to make arts activities available to a broad segment of Ohio's public; and secondly, by providing services that help to enhance the growth of the arts. There are a total of 7 different grant programs and a variety of service programs operated by the Council.

The Ohio Arts Council is committed to the economic, educational and cultural development of the state. The Council believes the arts should be shared by the people of Ohio. The arts arise from public, individual and organizational efforts. The OAC supports and encourages these efforts. Learn more about the Ohio Arts Council at <http://oac.state.us.gov>.

About VSA Ohio

VSA Ohio (VSAO) is the state organization on arts and disability. Founded in 1986, VSA Ohio advocates for accessibility and equality, advances careers in the creative sector, builds community, and improves the academic achievement of Ohio's students through arts integration. By bridging arts and disability, VSAO programs are conducted statewide and serve constituents of all ages and all disabilities. VSAO works in the classroom, galleries and public arena, where information and resources are shared with educators, artists and administrators. VSAO works to change perceptions about ability and disability by helping connect people to accessible, creative opportunities that inspire everyone.

VSA Ohio is member of the VSA Affiliate Network, a program of the John F. Kennedy Center for the Performing Arts. VSA is an international organization founded by Ambassador Jean Kennedy Smith in 1974. Learn more about VSA Ohio at www.vsao.org.