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The University of Toledo

Finding Aid

➤ **Autism Society of Northwest Ohio Records** ◀

MSS-240

**Size:** 3 linear feet

**Provenance:** Gift of the Autism Society of Northwest Ohio

**Access:** Open

**Collection Summary:** This collection contains administrative files, advocacy files, publications, audio-visual material, and artifacts.

**Subjects:** [Disability History](#)

**Related Collections:**

**Processing Note:**

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**Completed by:** Mimi Konicki, April 2010; last revised: November 2014

## **Autism Society of Northwest Ohio Records**

### **Historical Sketch**

Founded in 1968 (when the autism incident rate was 1/10,000), the Autism Society of Northwest Ohio (ASNO) is a chapter of the Autism Society of America (ASA), the oldest and largest autism-related grassroots organization in the country. The original name of Toledo's organization was the National Society for Autistic Children (NSAC). It was founded by parents of children with autism to provide support, education, and advocacy. Later the name changed to the Autism Society of America – ASA (12/11/87) and Ohio Autism Society (OAS), and the current organization name is Autism Society of Northwest Ohio (ASNO)

The organization's offices were located at One Stranahan Square (also known as the Community Services Building or United Way Building) from its founding until 2003. From 2003-2005, the organization was located at 241 N. Superior Street, and in 2005, the organization moved to 4848 Dorr Street, Suite #1. ASNO will again move to an as yet to be determined location in the summer of 2010.

In the early 1970s ASNO was placed by United Way under the United Health Services (UHS) umbrella along with several other disability organizations in order to share administrative costs. ASNO's 501 (c) 3 status was subordinate to UHS. During this time, UHS fundraisers such as the Rib Off and Taste of the Town provided a percentage of its profits to its affiliated organizations.

In 2005, when UHS disbanded, ASNO reorganized under the Autism Society of America 501(c) 3 status. At that same time, ASNO revised its bylaws and mission to reflect its core values. As a 501(c)3 corporation, ASNO is funded by United Way designations, grants, donations, memberships, autism awareness sales, fund raisers, and summer school fees.

ASNO's mission is to improve the lives of people affected by autism. ASNO's charter serves 12 counties in northwest Ohio: Lucas, Ottawa, Wood, Fulton, Defiance, Henry, Williams, Sandusky, Paulding, Putnam, Hancock and Seneca. ASNO is also affiliated with the Great Lakes Center for Autism and the Ohio Autism Coalition (OAC), the latter which serves as an umbrella organization for a multitude of autism related groups.

ASNO is an organization of parents, professionals, and other interested citizens working together to promote the general well being of people with autism living in Northwest Ohio. ASNO provides:

- Information about autism;
- Referrals to community resources;
- Support groups for families, including *Sibshop*;
- Family fun events such as picnics, Mud Hens games, a holiday party, and autism-friendly movies;
- Educational seminars for parents and professionals, including *Practical Solutions* workshops;
- Individual Education Plan (IEP) advocacy for school age children;

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- Extended summer school for children ages 3-22 who attend public schools (ESY);
- Awareness activities to promote understanding of autism;
- A Parent Resource Library with Boardmaker;
- Legislative and community advocacy;
- Website and quarterly newsletter, *Focus* (published in April, June, September, and December).

Currently, the ESY program is in its 18<sup>th</sup> year of affiliation with the University of Toledo. It is held 4 hours a day for six weeks.

Little information or detail exists from the 1980-1995 period for this organization. UHS provided oversight and records were not maintained with ASNO.

Below is a brief timeline of activities from the period 1977-2009.

### **2009:**

For consistency and branding, all Autism Society of America chapters nationwide adopted the same logo, which consisted of people in blue and white depicted as stars. The current slogan for the organization is “Improving the Lives of All Affected by Autism.” ASNO’s previous slogan—“The Voice and Resource of Autism in Northwest Ohio”—was represented by a logo consisting of a four piece puzzle. The puzzle’s 4<sup>th</sup> piece was separate and embedded onto it were the words “ASNO – Helping Solve the Puzzle of Autism.”

### **2008:**

Revenue was \$116,638.03; expenses were \$216,532.24; and investment income was \$54,601. Sources for revenue included 16% from United Way, 14% from donations, 6% from miscellaneous, 1% from fund raising, 27% from grants, and 36% from the summer school. Additional support came from France Stone, a Family Empowerment Grant from the Lucas County Board of Mental Retardation and Developmental Disabilities, and fundraisers, including “Give Autism the Boot.”

The Extended School Year (ESY) program served 30 students with autism spectrum disorder, and practicum experience was provided to 27 UT graduate speech/language students and 10 UT first year Occupational Therapy students observed in the program.

Some 337 participants attended the “17 Practical Solutions to Everyday Challenges” program held that year.

ASNO served as a member of the Lucas County Board of Mental Retardation and Developmental Disabilities’ Best Practices Committee; participated in the Autism Diagnosis Education Pilot Project focus group; trained 20 residents and medical students from UT’s medical college for its advocacy program; and arranged autism training for 38 Toledo Police Department law enforcement officials, 19 Wood County sheriff deputies, 4 members of the Oregon police, and 11 members of the Williams County police.

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### **2007:**

Executive director Linell Weinberg appeared on the local television show “Conklin & Company” for Autism Awareness Month. Also, the Great Lakes Center for Autism Community Resource Library was opened in April 2007 at ASNO’s facilities.

### **2006:**

“Give Autism the Boot,” a Great Lakes Center for Autism fundraiser, was held in the third week of June, and became an annual event.

In May, Executive Director Linell Weinberg sent a letter to pediatric practice office managers stating that according to the Centers for Disease Control, 1 out of 166 children born will develop an autism spectrum disorder. She then introduced herself and thanked Toledo Children’s Hospital for providing a kit developed by the CDC called *Learn the Signs, Act Early*. The kit provided resources for doctors and nurses to use to talk with parents about childhood development.

### **2005:**

Tom Billau (director of Student Services) created the position of Autism Intervention Specialist in response to the growing number of children with this disorder.

The 2005 the annual report, written by the president Melissa Mayfield, reported that ANSO was now part of the Great Lakes Center for Autism, a collaborative opportunity for many autism groups to come together to help provide more complete services to those affected by autism. ASNO appointed Linell Weinberg as Executive Director in order to better utilize her resources in an effort to provide more comprehensive services to the members

ANSO began a collaboration with the Lucas County MRDD Board, with board behavior specialists Jason Dura and Patrick Roper leading monthly support/social groups for adults with Asperger’s Syndrome at Lott Industries.

ANSO also collaborated with Mercy Hospital and Promedica to help plan and provide educational materials for two continuing education seminars for family practitioners and pediatricians about the early identification of autism. These seminars, presented by Dr. Karen Ratliff-Schaub, were also presented to Fulton County doctors and early intervention professionals at conferences.

ANSO represented people affected by autism on the Mayor’s Disability Committee, the MRDD Best Practices Committee, and the Toledo Public Schools’ Advocacy Committee. ASNO also publicized the first Ohio Autism Task Force forum held in June where many families and professionals testified about the needs of those affected by autism.

ANSO started another support group in Perrysburg.

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In September 2005, ASNO held the first annual “Rock for Autism” fundraiser at Centennial Terrace (which lost roughly \$800), and switched to “designations only” status with United Way of Greater Toledo.

In January 2005, a letter writing campaign occurred regarding the potential loss of Dr. Karen Ratliff-Schaub, a tireless advocate for disabled children in Toledo. Unfortunately, Dr. Ratliff- Schaub ultimately left the area to pursue opportunities in Columbus at Ohio State University.

### **2004:**

Scott D. Newsom of Eastman and Smith assisted with ASNO’s incorporation and re-organization and provided advice regarding ASNO’s tax-exempt status, formation of a non-profit corporation, and assistance with the change from subordinate group 501 (c) 3 status under United Health Services to subordinate group 501 (c) 3 status under the Autism Society of America.

A standing advisory panel composed of individuals with autism or family members of such individuals formed to advise the board of family and community needs and priorities. Members of the panel actively worked with the executive director to establish effective autism programs and services and to target fundraising proceeds.

Beginning in June 2004, ASNO undertook a series of strategic innovation sessions with Partners for Innovation. Stressing the need for staff leadership, authority, and follow through, the facilitator recommended the creation of an executive director position. The facilitator further noted that the relationship with UHS had crippled ASNO somewhat by displacing the executive director role and relying upon a surrogate director through UHS. The facilitator strongly recommended Linell Weinberg serve as the ASNO executive director.

In April, Barbara C. Yavorcik, chair of Ohio Autism Coalition (OAC), wrote to Ohio legislators to introduce them to OAC as a collation of autism advocacy organizations throughout Ohio working together with the Autism Task Force to speak with “one voice.” The OAC was formed to combine resources and to develop and implement statewide public policy addressing autism awareness and advocacy. ANSO was a member of the group.

The four main functional needs discussed in strategic planning sessions were: public awareness and membership, fundraising, operations, and autism services.

### **2002:**

Linell Weinberg became the outreach coordinator. She earned a bachelor’s degree in early childhood education in 1974 and a master’s degree in social work in 1976, both from the University of Michigan. Weinberg’s own daughter was 18 when she was diagnosed with a form of autism known as Asperger’s syndrome.

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The Board of ANSO declined an invitation from the Ohio Association for Retarded Citizens to join the group because in the past autism was often considered a form of mental retardation or mental illness, but it was now regarded as a distinct neurological disorder.

In May, Barb Yavorcik, president of ASNO, stated that the organization planned to file a complaint with the Ohio Department of Insurance regarding insurance coverage exclusions for diagnosing autism. She stated her belief that this was discrimination, and wanted to know if any of the other chapters were aware of any other insurance companies in Ohio that have such an exclusion for the diagnosis of autism.

### **2001:**

The annual meeting was held in July at Brandywine Country Club, with the Bittersweet Farms Hand Bell Choir performing.

In January, ASNO made an agreement with United Health Services to hire Carol Holmes to provide information and support to family members of children and adults with autism, provide crisis counseling by telephone, respond to all telephone contacts, facilitate client access to appropriate services as well as other services, at an hourly rate.

### **1999:**

In July, Barb Yavocik, president of ASNO, prepared a grant proposal with the goal to provide the health care component of a child and family development program in collaboration with parents, primary care providers, school systems and community services or agencies. Appendix A of this document was entitled "Developmental Disabilities NW Ohio and Overview." It stated that county boards of MRDD in Lucas, Ottawa, and Wood identified 3,070 individuals who received their services. She stated that autism, a low incidence developmental disability, typically occurs in 15 out of 10,000, representing 975 cases in the tri-county area.

### **1997:**

The board met on March 7 and reviewed the proposed standards from the state education department regarding the definition of autism.

Some 68 people attended a meeting at the Ability Center of Toledo hosted by Sue Hetrick and facilitated by Alicia Curry of ASNO. Representatives of ABLE and the Equal Justice Foundation attended. Dr. Merrill Grant (Toledo Public School superintendent) was invited but did not attend. Parents, many with autistic children, gave personal testimony.

### **1996:**

ASNO applied to the Knights of Columbus for a grant for its Extended School Year (ESY) Program. The grant application stated that autism is a life long severe disability with no known cause or cure and it occurs in 15/10,000 births. The summer program was ASNO's largest annual expenditure.

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Tom Rothwell met with Jerry Lee, president of Autistic Community of Northwest Ohio and discussed the need for cooperation between ANSO and the Autistic Community to avoid holding events and membership drives simultaneously and causing confusion in the community.

### **1978:**

On January 13-14, there was a workshop in Columbus about parents' rights, and three from this ASNO chapter attended. It was sponsored by the Ohio Autistic Society

## **Autism Defined**

Autism is a problem understanding messages from the senses, especially sight and hearing. When messages from eyes and ears reach the brain, they are not linked into an understandable picture of the outside world. This leads to a lack of understanding of speech and gesture, which results in a lack of ability to communicate. Because of this, children with autism appear to be withdrawn and seem to live in an isolated world of their own.

Autism, a complex developmental disability typically appearing before age three, affects a person's ability to communicate and interact with others. Often found in combination with other disabilities, autism is also a spectrum disorder that affects individuals differently and to varying degrees of severity. This results in a unique learning style profile for each individual.

Autism is more common than childhood cancer, cystic fibrosis, and MS combined. While there is no known cause, a combination of genetic predisposition and environmental triggers is suspected. In 1976, 1 out of 10,000 children were diagnosed with autism. Later research indicated that autism occurred in about 15 out of 10,000 births and was 4.5 times more common in boys than girls. In 2002 there was one autistic child out of every 500. In 2009 it is one out of every 110. According to the U.S. Department of Education, the incidence of autism is increasing by 10-17% a year. Roughly 10,000 to 15,000 live with autism in Ohio, many of whom are undiagnosed. Today 1 to 1.5 million Americans have ASD (Autism Spectrum Disorder).

This neuro-biological brain disorder affects communication, social skill development, and behavior. It impairs social interaction and communication, and it causes restricted and repetitive behavior. The hallmark of autism spectrum disorder is uneven development. People with autism may have trouble understanding and using language and interacting with other people. Some exhibit repetitive behaviors or have sensory integration problems. People with Asperger's Syndrome, a highly verbal form of autism, can be very intelligent but lack social skills.

Although there exists no cure for autism, today experts know that intensive therapy and keeping the child in a family setting is the better alternative to institutionalization. Early intervention is the key. The National Academy of Sciences recommends that children

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receive 25 hour a week of services, which can include speech therapy, behavioral therapy, and therapy for sensory problems. Beneficial therapies include: Applied Behavior Analysis (ABA), Discreet Trial Training (DTT), Early Intensive Behavioral Intervention (EIBI), Speech therapy including the use of Picture Exchange Communication Systems (PECS), Sensory Integration therapy, and Social Stories.

The cost of caring for a child with autism has been estimated by the Autism Society of America (ASA) to be from \$3.5 million to \$5 million. The United States faces nearly \$90 billion each year in costs for autism, which includes research, insurance costs and non-covered expenses, Medicaid waivers for autism, educational spending, transportation, housing, caregiver costs and therapeutic services.



## **Autism Society of Northwest Ohio Records**

### **Scope and Content Note**

The records of the Autism Society of Northwest Ohio (ASNO) are divided into six series by type and function of record. The files within each series are arranged first alphabetically and then chronologically.

**Series I, Administrative Files,** documents all aspects of the administration of the organization. Because the organization was a part of United Health Services for much of its existence, most of these files date from 2005 when the group left UHS and became affiliated with the Autism Society of America. Of particular note are copies of the organization's newsletter, *Focus*.

**Series II, Advocacy Files,** documents activities ANSO on behalf of its clients. Several folders concern the Mayor's Commission on Disabilities, and the work of ASNO executive director Linell Weinberg on that commission. Other folders document work at the state level to pass legislation on behalf of those with autism.

**Series III, Publications,** consists of published materials, some from other autism society chapters, concerning autism topics. These materials should prove useful to researchers looking for reference materials on the topic of autism and related subjects.

**Series IV, Autism Society of America,** documents work of the national organization on behalf of autism. Of note are copies of the organization's newsletter, *Advocate*, dating from 1991 to 2004.

**Series V, Programming,** consists of information on programs offered about autism by ASNO. Some topics overlap with those in the Advocacy series and Publications series.

**Series VI, Audio-Visual and Artifacts,** consists of video tapes of local and national programs on various subjects, including recordings of ASNO annual awards banquets. Artifacts consist of two t-shirts from local ASNO fundraisers.

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**Folder List**

<b>Box</b>	<b>Folder</b>	<b>Item</b>
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1	2	ARC meetings, 1996-2004
1	3	Articles on local chapter, 2004-2008
1	4	ASNO agreement for information and referral specialist, 2001
1	5	ASNO annual meetings, 2001-2005
1	6	ASNO articles of incorporation, 2004
1	7	ASNO assessment by Partners for Innovation, 2004
1	8	Autism Forum of Northwest Ohio meetings, 2003
1	9	Autism Society of Ohio, annual conference, 2007
1	10	Autism Society of Ohio annual conference, 2002-2003
1	11	Benefits and requirements of becoming affiliated nationally, 2004
1	12	Board meetings, 2007
1	13	Board meetings, 2004
1	14	Board meetings, 2003
1	15	Charter school opening, 2001
1	16	Code of Regulations Committee, n.d.
1	17	Collaborative Committee reports, 2004
1	18	Elimination of autism intervention specialist, 2007
1	19	Financial information, 2005
1	20	<i>Focus</i> newsletter, 1997
1	21	<i>Focus</i> newsletter, 1998
1	22	<i>Focus</i> newsletter, 2000
1	23	<i>Focus</i> newsletter, 2001
1	24	<i>Focus</i> newsletter, 2002
1	25	<i>Focus</i> newsletter, 2003
1	26	<i>Focus</i> newsletter, 2004
1	27	<i>Focus</i> newsletter, 2005
1	28	<i>Focus</i> newsletter, 2006
1	29	<i>Focus</i> newsletter, 2008
1	30	Grant opportunities, 2004-2006
1	31	Grant proposals, 1996, n.d.
1	32	Job descriptions, n.d.
1	33	Letters to MCO re: Dr. Ratliff-Schwab, n.d.
1	34	Logos and addresses, n.d.
1	35	Lucas County Collaborative, 2004
1	36	Meeting minutes, 1977
1	37	Meeting minutes, 1978
1	38	Meeting minutes, 1979
1	39	Meeting minutes, 1980
1	40	Meeting minutes, 1997
1	41	Meeting minutes, 2005

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1	42	Members of the board, 1979-2002
1	43	Northwest Ohio Regional Autism Advisory Council, 2005
1	44	Northwest Ohio Regional Autism Advisory Council, 2006
1	45	Northwest Ohio Regional Autism Advisory Council, 2007
1	46	Notes from chapter leader meeting, 2005
1	47	Planning and Development Committee, 2000-2004
1	48	Project on advertising assistance, 2001
1	49	Regional autism advisory council members, 2005
1	50	Regional Autism Advisory Council of Southwest Ohio, 2003
1	51	Request for funding, France Stone, 2004
1	52	Service contract, UHS/ARC of Lucas County, 2003-2004
1	53	Strategic plan, 2004-2005
1	54	Survey on autism spectrum disorder for charter school, 2002
1	55	Quarterly report, 2005
1	56	United Health Services 501 © 3 status, 1989
1	57	United Health Services, 2002-2004
		<b>Series II. Advocacy Files</b>
1	58	Abbreviations, 2002
1	59	Autism Awareness Day, n.d.
1	60	Autism general fact sheet, n.d.
1	61	Autism license plates, 2007
1	62	Autism researcher demographics, 2006
1	63	Autism resource list, 2003
1	64	Autism Society of Ohio update, 2003
1	65	Autism support waiver, n.d.
1	66	BGSU petition for teachers of autism, 2002
1	67	BGSU student study, 2004
1	68	City law office—Commission on Disability, 2004
1	69	Commission on Disability, 2005
1	70	Disability data report, 2005
1	71	Disability expo exhibit, 2007
1	72	Exhibit—Collaborative Network—“Building Allies for Children,” 2005
1	73	IDEA, 1997-2001
1	74	Legislative Committee meeting, 2006
1	75	Legislative Committee meeting, 2006-2007
1	76	Letter to pediatric physicians, 2006
1	77	Level One waivers, 2003
1	78	Lucas County MRDD Board Action Plan, 2003
1	79	Martin settlement, n.d.
1	80	Miscellaneous school information, 2000-2002
1	81	Ohio legislator articles, 2007
1	82	Mayor’s Commission on Disability, 2005

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1	83	Mayor's Commission on Disability, 2006
1	84	Mayor's Commission on Disability, annual report, 2005
1	85	Mayor's Commission on Disability, appointment of Weinberg, 2004-2005
1	86	Mayor's Commission on Diversity—correspondence, 2005
1	87	New rule for severely disabled students, 2003
1	88	Northwest Ohio Special Education Regional Resource Center, 2004
1	89	Ohio Autism Coalition, 2003-2006
1	90	Ohio Autism Coalition, 2006
1	91	Ohio Autism Task Force, 2003-2004
1	92	Ohio budget for autism, 2003
1	93	Ohio Center for Autism, 2006
1	94	Ohio Department of Insurance, 2002
1	95	Ohio legislature, 2003
1	96	Ohio Olmstead Task Force, n.d.
1	97	Ohio Statewide Parent Mentoring Meeting, 2003
1	98	Omnibus bill, 2004
1	99	Operating standards for Ohio schools, 2002
1	100	Regional Autism Advisory Council, 2004
1	101	Securing special education services in northwest Ohio, 1992
1	102	Special needs fair, 2004
1	103	Studies of autism, 2003-2005
1	104	Toledo Issue 2, 2002
1	105	Toledo ordinance 577-05, 2005
1	106	Toledo Public Schools Coalition, 2003-2007
1	107	University Hospitals—Cleveland neuro-psychological study, 2002
1	108	Vision for Transforming symposium, 1996
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2	1	Autism seminar handout, 2001-2005
2	2	Autism service guidelines, 2004
2	3	Autism Society of Michigan newsletter, 2002
2	4	Autism Society of North Carolina newsletter, 2002
2	5	Autism Society of Ohio and Indiana conference, 1995
2	6	Autism Society of Ohio and Indiana conference, 2004
2	7	Asperger's Syndrome newsletter, 2002
2	8	Autism articles, 1994
2	9	Autism articles, 1998-2004
2	10	Autism articles, n.d.
2	11	Autism conference, 2002-2004
2	12	Autism for the holidays, 2002
2	13	Books/video resources/references, 1994-1997
2	14	Broadcasts about autism, 2000-2001
2	15	Choosing/customizing education curricula, 2002
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2	17	Educating Asperger's Syndrome children, 1992-2002
2	18	Excellence in autism research, 2002
2	19	Frequently asked questions, 2006
2	20	"How They Grow," 1981
2	21	<i>Journal of Autism and Developmental Disorders</i> , 1996
2	22	<i>Journal of Autism and Developmental Disorders</i> , 1996-1997
2	23	Next Steps—A Guide to Families with Autism, 2004
2	24	Parent alliance, 2004
2	25	Parent and Family Issues: Stress and Knowledge, 1998
2	26	"Rolling Out, Looking Up," 2003
2	27	"Tips for Teachers Working with ASD," 2003
2	28	"Where is the Manual?," 2006
		<b>Series IV. Autism Society of America</b>
2	29	<i>Advocate</i> , 1991
2	30	<i>Advocate</i> , 1992
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2	32	<i>Advocate</i> , 1994
2	33	<i>Advocate</i> , 1995
2	34	<i>Advocate</i> , 1996
2	35	<i>Advocate</i> , 1997
2	36	<i>Advocate</i> , 2000
2	37	<i>Advocate</i> , 2001
2	38	<i>Advocate</i> , 2002
2	39	<i>Advocate</i> , 2003
2	40	<i>Advocate</i> , 2004
2	41	Awareness packet for chapters, 2005
2	42	Brochures in English and Spanish, n.d.
2	43	Chapter manual, 2000 (1)
2	44	Chapter manual, 2000 (2)
2	45	Chapter manual, 2000 (3)
2	46	Chapter manual, updates, 2000-2002
2	47	Conference, 1994
2	48	Conference, 2003
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2	50	Facilitated communication, 1998
2	51	Services and benefits, n.d.
		<b>Series V. Programming</b>
2	52	ASNO—Challenges to Autism, n.d.
2	53	ASNO events, 2001-2008
2	54	ASNO Extended School Year, 2005-2009
2	55	ASNO Extended School Year evaluation, 2004
2	56	ASNO presentations, 2006-2007
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2	58	Autism Academy of Learning, 2008
2	59	Autism Awareness month, n.d.
2	60	Autism programming seminars, 2003-2005
2	61	Autism fact sheet, n.d.
2	62	Child and family development program, 1997
2	63	Junior League Health/Wellness Forum, 2004
2	64	Local conferences for children with special needs, 2004-2006
2	65	Oasis charter school, 2003
2	66	Ohio Autism Academy, 2006
2	67	PowerPoint presentations, 2006
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2	70	Sample IFSP outcomes for ASD, n.d.
2	71	Scheduled local autism events, 2004-2010
2	72	Sibling program, n.d.
2	73	Suggested questions for referring children for speech therapy, n.d.
2	74	Table exhibits, 2002-2007
		<b>Series VI. Audio-Visual and Artifacts</b>
3	1	Autism awards banquet, 1989
3	2	Autism awards banquet, 1990
3	3	Autism awards banquet, 1992
3	4	Autism month, 2004
3	5	"Autism Out of the Darkness," n.d.
3	6	Autism Society of America PSA, 1995
3	7	Autism television spots, n.d.
3	8	Nancy Minshew seminar, n.d.
3	9 (box)	Fundraiser t-shirt, "Rock for Autism," n.d.
3	9 (box)	Fundraiser t-shirt, "Dance for a Chance," n.d.