

NIH Autism Centers of Excellence: A Feasibility Study for Program Evaluation



Management Report

National Institutes of Health

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National Institute of Deafness and Communication Disorders
National Institute of Environmental Health Sciences
National Institute of Mental Health
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Background on Autism Spectrum Disorders and the Autism Centers of Excellence Program

Autism spectrum disorders (ASD) are a group of neurodevelopmental disorders characterized by core deficits in three domains: social impairments, communication difficulties, and repetitive or stereotypical patterns of behavior. No diagnostically informative biomarkers exist for ASD; diagnostic criteria are largely behavioral. Other developmental, behavioral, psychiatric, and medical conditions commonly co-occur with ASD.

ASD are common disorders, second in frequency only to intellectual disability among the serious developmental disorders. ASD occur more commonly in boys, with the average male-to-female ratio of 4.3 to 1. More children are being diagnosed with ASD today than in the past. Some of the prevalence increase is probably attributable to changes in diagnosis and classification; however there are insufficient data to determine whether this can explain the entire increasing trend.

Currently, there is no cure for ASD and treatments are limited. In an effort to intensify efforts to find the causes of ASD and identify new treatments, and in accordance with the Combating Autism Act of 2006, NIH created the Autism Centers of Excellence (ACE) program in 2007. In 2009, to help inform future decisions about investments in autism research and improve coordination and implementation of the ACE program a feasibility study was conducted by MasiMax Resources, Inc. (now RTI International) and The Madrillon Group Inc. in collaboration with the NIH Autism Evaluation Implementation Oversight (AEIO) Working Group.

The Combating Autism Act of 2006, Public Law No. 109-416¹, signed into law on December 19, 2006, authorized NIH “to expand, intensify, and coordinate” research activities related to ASD and to consolidate activities if consolidation “would improve program efficiencies and outcomes.” Consistent with the Act, the NIH created the Autism Centers of Excellence (ACE) program in 2007. The

¹ http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=109_cong_public_laws&docid=f:publ416.109

Combating Autism Act (CAA) and the NIH Reform Act of 2006 also require that NIH report to Congress on periodic reviews to evaluate the performance and research outcomes of the ACE program. To implement this requirement, the NIH formed the Autism Evaluation Implementation Oversight (AEIO) working group, with members representing the five NIH Institutes that provide financial support and expertise to the ACE program. The AEIO working group has overseen this feasibility study for evaluating the ACE program.

The NIH ACE program consists of research centers and networks focused on identifying the causes of ASD and developing new and improved treatments. In 2007, five ACE Centers and two ACE Networks received funding. In 2008, one additional ACE Center and three additional ACE Networks were funded. Together the ACE Centers and Networks accounted for approximately \$17 M in NIH spending for FY 2007, \$25 M in FY 2008, and \$26.5 M in 2009.

Exhibit 1 shows the ACE Centers and Networks funded in 2007 and 2008. Five of the six ACE Center Principal Investigators (PIs) had prior involvement with the STAART and/or CPEA programs. Three of the five ACE Network PIs had prior involvement with STAART and/or CPEA programs.

Exhibit 1: ACE Centers and Networks Funded in 2007 and 2008

Institution	Center/ Network	Year Funded	Funding Mechanism	PI Prior Program Involvement
University of Illinois at Chicago	Center	2007	P50	CPEA
University of California, San Diego	Center	2007	P50	
University of Washington	Center	2007	P50	STAART
University of Pittsburgh	Center	2007	P50	CPEA
University of California, Los Angeles	Center	2007	P50	CPEA
University of North Carolina at Chapel Hill	Network	2007	R01	STAART & CPEA
University of California, Davis	Network	2007	U01	CPEA
Yale University	Center	2008	P50	STAART & CPEA
Wayne State University	Network	2008	R01	
University of California, Los Angeles	Network	2008	R01	STAART
Drexel University	Network	2008	R01	

ACE Centers² are designed to foster collaborations between teams of specialists, who share the same research facilities so that they can conduct a set of interdependent and interrelated research projects. ACE Centers must include a minimum of three but no more than six research projects. The addition of core support services that facilitate research projects is optional depending on specific needs.

ACE Networks³ consist of researchers at multiple facilities throughout the country, all of whom work together on a single research question or project. Because networks encompass multiple sites, they can recruit large numbers of study participants. ACE Networks are required to have a Data Coordinating Center (DCC) that operates independently from data collection sites and acts as the network's interface with the National Database for Autism Research. The ACE Centers and Networks are expected to contribute their human subjects-related data to the National Database for Autism Research (NDAR) to facilitate data sharing and collaboration (<http://ndar.nih.gov/ndarpublicweb/>).

Evaluation Questions, Methods, and Data Sources

The AEIO working group proposed preliminary questions for ACE program evaluations:

1. What research topics, areas of research, and types of Autism Spectrum Disorders (ASD) research have been addressed by the ACE Centers and Networks?
2. What publications and research advances have resulted from the ACE program?
3. Has the structure and organization of the ACE program provided opportunities for interaction and communication within and across the ACEs?
4. Since the establishment of the ACE program, how many subsequent applications have been submitted to NIH by ACE researchers?
5. Has the ACE program attracted experienced researchers from other fields to ASD research?

² Funded under a P50 mechanism, RFA-HD-06-016.

³ Funded under R01 and U01 mechanisms, RFA-HD-06-004.

6. Has the ACE program attracted (post-doctoral) trainees and young (new) investigators to ASD research?
7. What lessons can be learned from the experience of the ACE program for building new research capacity in ASD research?

The feasibility study encompassed a number of tasks and activities designed to provide baseline data and determine the feasibility of these questions. These included:

- a review of prior program evaluations of NIH research center and network programs;
- a review and analysis of review articles published in the ASD research literature between January 1, 2007 and July 1, 2009;
- a review and analysis of ACE Center and Network publications published between October 1, 2007 and July 1, 2009;
- interviews with ACE stakeholders and participants (ACE investigators and NIH ACE POs) to obtain perspectives on the ACE program;
- a review of information about NDAR's design, policies and procedures, and data contents and submission records;
- data abstraction from the ACE Center and Network grant applications and annual progress reports (APRs), to identify the types and quality of the data elements routinely reported in the grant applications and APRs and to collect baseline data on the ACE Centers and Networks for future evaluation activities; and
- data analysis of ACE investigators' previous and subsequent NIH grant applications and publications.

Findings from the Baseline Data for the ACE Program

Organization and Staffing of the ACE Centers and Networks

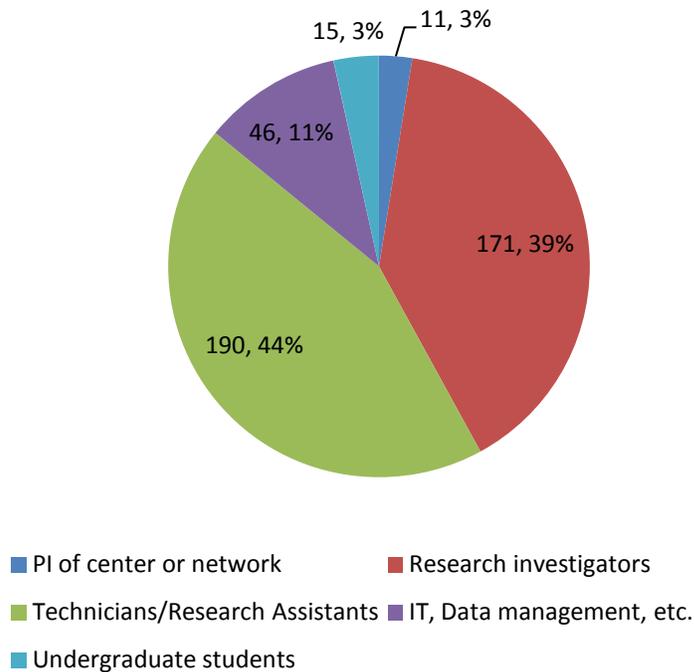
The ACE program includes both Centers and Networks. ACE Centers are comprised of: (a) research projects, each with its own scientific objectives; and (b) research cores, which are used to support common activities across several research projects. Each ACE Center includes an administrative and a clinical core, and many have other cores to provide services in such areas as imaging or genetics.

While the ACE Centers include several related research projects, usually at a single university site, ACE Networks are designed to enable researchers to conduct studies by recruiting participants at multiple clinical sites, often at universities in different areas of the country. Each ACE Network includes multiple research sites and a data coordinating center to coordinate data management and analysis. Some of the ACE Networks also include other cores to provide additional services across Network sites. For example, the ACE Network administrated by the University of North Carolina includes an Imaging Core to process brain imaging data gathered at each research site.

In 2008-2009, a total of 432 staff were identified in progress reports as supported in whole or in part by one of the ACE Centers or Networks. Of this total, 181 individuals were identified as research investigators, including the 11 ACE Principal Investigators. Other staff supported under ACE Centers and Networks included research assistants (including administrative staff, although few of these were identified), and IT and data management staff. Exhibit 4.2 shows the total distribution of staff by the role in the ACE program, for all ACE Centers and Networks combined. ⁴

⁴ Roles were identified by descriptions provided in the grantee progress report. Because different PIs may use different descriptions for individuals with similar activities, these categories may be best viewed as approximations.

Exhibit 2: Number and Percent of Staff by Role in the ACE Center or Network, FY 2008-2009



Each grant supported from 24 to 59 full and part time staff including from 9 to 22 research investigators. The majority of ACE investigators (61 percent) held a PhD degree, and a relatively small proportion (8 percent) held both an MD and a PhD. The PIs of the ACE Centers and Networks were also more likely to have a PhD (7 of 11), while 2 had both an MD and a PhD and two had an MD only.

Publication and NIH Grant History of ACE-Supported Research Investigators – updated in April 2012 (see updated text below in red)

ACE Investigators Publication History

In the 2008-2009 period of the ACE program, the ACE Centers and Networks had attracted a group of senior, experienced researchers. The ACE PIs were senior leaders in the field of autism research. The other investigators were largely senior or mid-career researchers, with a relatively smaller number of junior investigators. About 97 percent of all ACE investigators were

published researchers, many in well-regarded journals. About 87 percent of investigators had published in 2000 or before, and nearly half (48 percent) had published in 1990 or earlier.

The previous publications of the ACE researchers have appeared in a wide variety of well-regarded journals. These included a mixture of autism specialty journals, psychiatric journals, and prestigious general interest journals. Exhibit 3 shows the most common journals for ACE investigators, throughout their careers as well as **since 2000**. Recently, a greater number of the ACE researchers' articles have appeared in prestigious, general interest journals. This may reflect the maturing of the ACE investigators' careers, increasing awareness and interest in autism research, or both.

Exhibit 3: Most Common Journals for ACE Investigators

Note: these numbers have been updated since the previous report, to reflect totals through March 2012.

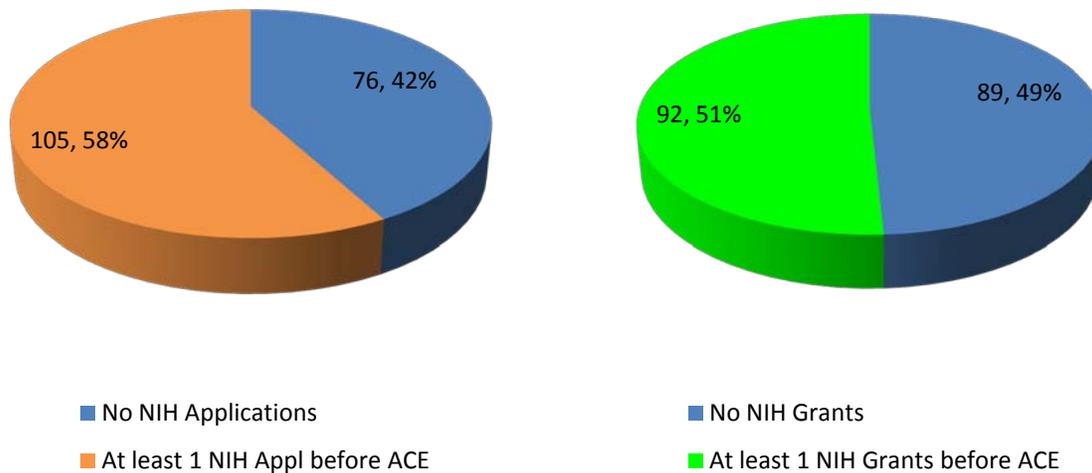
Rank	Journal	Type of Journal	Career Totals		Since 2000	
			Number of ACE Investigators	Number of Articles	Number of ACE Investigators	Number of Articles
1	Journal of Autism and Developmental Disorders	Specialty Autism	70	368	67	271
2	Biological Psychiatry	Psychiatry	69	177	62	117
3	American Journal of Psychiatry	Psychiatry	59	196	53	120
4	Journal of the American Academy of Child and Adolescent Psychiatry	Psychiatry	53	198	49	126
5	Archives of General Psychiatry	Psychiatry	51	114	48	83
6	Proceedings of the National Academy of Sciences of the	Other (including general interest)	47	164	40	120

Rank	Journal	Type of Journal	Career Totals		Since 2000	
			Number of ACE Investigators	Number of Articles	Number of ACE Investigators	Number of Articles
	United States of America					
7	Pediatrics	Other (including general interest)	47	103	40	62
8	NeuroImage	Neurology	44	194	44	121
9	Nature	Other (including general interest)	45	60	38	39
10	American journal of human genetics	Genetics	44	233	42	117
11	Neurology	Neurology	42	129	35	75

ACE Investigators' Grant History

As Exhibit 4 shows, the majority of the ACE investigators (58 percent) had submitted at least one NIH application, and the majority (51 percent) had received at least one NIH funded grant as a Principal Investigator before the start of the ACE program. All of the ACE PIs had submitted applications to NIH and received at least one NIH grant.

Exhibit 4: ACE Investigators' Prior NIH History, Applications and Grants



Many of the ACE investigators were currently, or had been in the past, PIs on NIH research grants, including R01 grants. As of 2009, about 69 percent of the 92 ACE investigators who received a previous grant had held an R01; similarly, 35 percent had received a training or career development grant and 29 percent had received a cooperative agreement.

Update as of April 2012

As of early 2012, some of the investigators associated with the ACE centers had obtained their first R01 grants since 2009. Of ACE investigators that had received a previous grant, the percent that received an R01 grant grew substantially, from 69 to 81 percent, between 2009 and 2012. The percentage of these investigators that received training grants and cooperative agreement grants, however, changed very little after 2009 (from 35 to 37 percent and from 29 to 30 percent).

ACE investigators were able to take advantage of the additional research opportunities afforded by the American Recovery and Reinvestment Act (ARRA) in 2009-2010. The NIH used ARRA funding to issue a series of Funding Opportunity Announcements (FOAs) targeted specifically to autism research. Autism research

was also included in the NIH-wide FOA for “challenge grants” under ARRA. Moreover, ARRA funding enabled NIH to support investigator-initiated grants that would not have been funded otherwise. In 2009 and 2010, a total of 30 new ARRA grants were awarded to the ACE investigators. This total included 14 R01 grants; 9 of these R01 awards were made as part of the autism-specific ARRA FOAs. Several of these grants went to investigators who had not previously received an R01 grant from the NIH.

In addition to the R01s, the ACE investigators received 12 ARRA-specific “Challenge grant” and “GO grant” awards. The “Challenge Grant” program supported high-impact research to address specific scientific and health research challenges that could benefit from significant 2-year jump-start funds. Autism was one of the over 100 topics eligible for Challenge Grant funds. The “Grand Opportunities”, or “GO Grants”, were designed to support large-scale, high impact research. Both the Challenge and GO grants were extremely competitive. For the NIH as a whole, approximately 4 percent of applicants were successful in receiving a Challenge Grant; the funding rate for the GO grants was approximately 15 percent.

Research Topics and Areas of Research Addressed by ACE Centers and Networks

The field of autism research is relatively broad. In order to improve outcomes for children with ASD, clinicians and scientists will need more information about the causes and mechanisms, risk factors, diagnosis, prevention and treatment interventions, access to care, quality of life, adherence, and other areas. Stakeholders, ACE PIs and site PIs, and NIH Program Officers for the ACE program were asked to identify the most important areas for research on ASDs. There was strong consensus on the most important areas across all three groups that intervention and treatment research, etiology and genetics research were the most important areas, although other topics were also frequently mentioned. Research concerning the possible relationship between autism and childhood vaccination was mentioned consistently as a low priority area among stakeholders, investigators, and program officials.

For the 13 stakeholders, the most important research areas to target are listed below, with the number of respondents given in parentheses:

- Intervention and treatment research (11);
- Genetics research (7);
- Aging and lifespan issues (6);
- Etiology of autism (4);
- Behavioral research (3);
- Detection and early diagnosis (2); and
- Environmental research (2).

Stakeholder groups stressed the importance of keeping both the short- and the long-term in mind in autism research. Stakeholders stressed the long-term benefits of basic research, particularly genetics, in identifying and addressing the basic causes and mechanisms behind ASD. At the same time, the stakeholder groups pointed out that families affected by ASD need better treatment options now. Treatment and other intervention research was mentioned by the greatest number of stakeholder groups.

Stakeholders were hesitant to identify less important research areas. The only area frequently cited as a less important priority was vaccine research. With one exception, stakeholder groups felt that the vaccine issue had been resolved by science and should not be a continuing priority.

For the 11 ACE PIs and the 5 network site PIs, priority areas mentioned in the interviews included:

- Genetics research (11);
- Intervention and treatment research (9);
- Neuropathology and neurobiology (5);
- Aging and lifespan issues (3);
- Environmental research (3);
- Etiology (3);
- Behavioral research (2); and
- Detection and early diagnosis (2).

ACE investigators stressed the importance of genetics research most often, but intervention and treatment research was also a top priority. NIH program officers as a group agreed with these priorities. Investigators and program officers mentioned the need for basic and clinical researchers to work together to identify and address the causes and mechanisms of ASDs.

ACE Research Projects

The descriptions of the ACE research projects provided in the grantee progress reports indicate that the ACE Centers have focused on those areas indicated by stakeholders, investigators, and program officials as key priorities. Specifically:

- Nearly all the ACEs (10) incorporated research projects to identify, confirm, or measure biological (including genetic) mechanisms associated with autism spectrum disorders;
- New methods to diagnose autism spectrum disorders were researched by 8 ACEs;
- New treatments or methods of prevention were under investigation in 7 ACEs;
- Over half (6) ACEs included research projects to identify, confirm, or measure the impact of risk factors for autism.

Leveraging Additional External Funding for the ACE Centers and Networks

updated in April 2012 (see updated text below in red)

The ACE Centers and Networks reported receiving additional funding beyond their ACE grant from a wide variety of sources, from other NIH institutes, other federal agencies, nonprofits, and other private sources. It proved difficult to distinguish between funding that is provided to ACE investigators for related research and funding that directly serves the projects, objectives, and activities of the ACE Center or Network. However, the wide range of other funding sources indicates that the investigators of the ACE Centers and Networks have leveraged funds from multiple sources.

Exhibit 5 shows the number of NIH Institutes and Centers (ICs) credited with providing funding to the ACE and/or its investigators

beyond the funding provided via the original ACE grant and direct supplements to the original ACE grant. Three of the 11 ACEs received additional funding from a majority of the 27 NIH Institutes and Centers, and all the ACEs received funding from at least **6** NIH ICs.

Exhibit 5: ACEs by Number of NIH Institutes and Centers (ICs) Credited with Other Funding (beyond ACE Grant)

Grant	Center or Network	Number of NIH ICs Credited with Other Funding
K	Network	18
H	Network	16
C	Center	14
G	Center	12
E	Center	12
F	Center	11
A	Network	11
J	Network	10
I	Network	8
B	Center	8
D	Center	6

Exhibit 6 shows that the NIH ICs that collectively fund the ACE Centers and Networks are, unsurprisingly, the most common sources of additional NIH funding. All the ACEs received additional funding through NIMH, NICHD, and NINDS in 2008-2009.

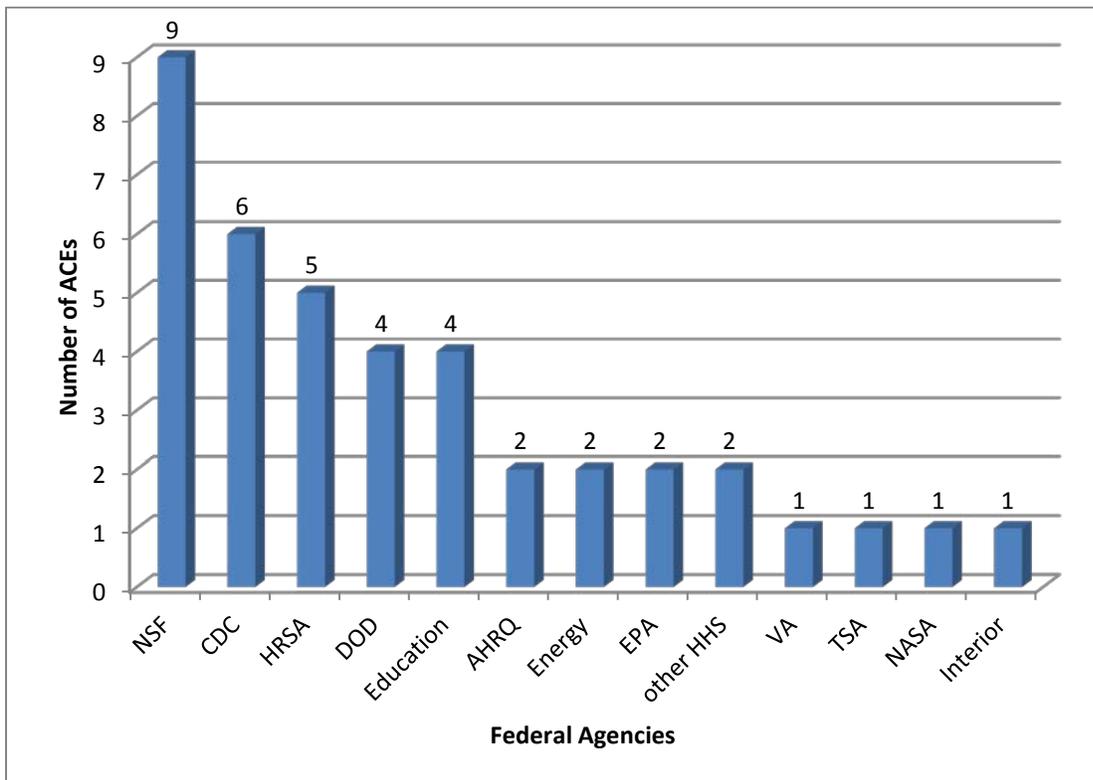
Exhibit 6: NIH Institutes and Centers (ICs) Providing Additional Funding to ACEs and Their Investigators

IC	Number ACEs crediting this IC for additional NIH funding
NIMH	11
NICHD	11
NINDS	11
NIDCD	10
NIDA	10
NIA	10
NHLBI	9
NCRR	7

NCI	7
NIBIB	5
NIGMS	6
NEI	5
NHGRI	6
NIAAA	5
NIAMS	4
NIDDK	4
NIEHS	6
FIC	3
NIAID	3

Other Federal agencies also supported the ACEs and their investigators. Exhibit 7 shows the other Federal agencies that reportedly supported ACEs and their investigators. The individual ACE Centers and Networks that received funding from the greater number of NIH ICs also tended to receive funding from a greater number of other Federal agencies. **These numbers stayed the same from 2009 to 2011-2012.**

Exhibit 7: Other Federal Funding Sources for ACE Centers and Networks



ACE Centers and Networks also reported receiving funding from non-federal sources, including foundations, advocacy groups, state and local governments, and others. All the ACEs reported receiving funding from foundations and advocacy groups.

The ACEs varied substantially in the number of non-federal funding sources described as supporting the ACEs and/or their investigators. As Exhibit 8 shows, several of the ACEs reported a large number of non-federal funding sources, whereas others reported only a few. With one significant exception, the Networks tended to report a larger number of non-federal funding sources when compared with the Centers. **The number of non-federal funding sources per center grew slightly between 2009 and 2012.**

Exhibit 8: Number of Non-federal Funding Sources Reported per ACE Grant

Grant	Center or Network	Number of Non-Federal Funding Sources
K	Network	44
A	Network	42
J	Network	29
C	Center	22
H	Network	21
F	Center	18
E	Center	17
D	Center	15
G	Center	13
B	Center	10
I	Network	9

Many individual organizations supported one or two ACE Centers or Networks. However, there were a small number of nonprofit organizations that were reportedly supporting a larger number of ACEs and their investigators. These included:

- Autism Speaks (all 11 ACEs);
- Simons Foundation (**9**);
- Cure Autism Now (7); and
- National Alliance for Autism Research (6).

The non-federal organizations that supported ACE centers and networks remained largely the same between 2009 and 2012.

The Role of NDAR in the ACE Program

The NIH developed NDAR as a secure bioinformatics platform for scientific collaboration and data sharing for ASD investigators. Along with the ACE program, the majority of ASD research projects recently funded through the Recovery Act, as well as ASD studies conducted in intramural laboratories at NIH, are also expected to submit and share data through NDAR. Other ASD researchers have been encouraged to add their study data, regardless of funding source, and NDAR staff are transferring data from earlier NIH programs, such as CPEA and STAART, into NDAR as well.

One of the first steps in the data submission process is completing a Data Submission Agreement with NDAR. As of April 2010, all ACE Centers and Networks had Data Submission Agreements in place. The first agreement was submitted on January 8, 2008 and the last agreement was completed on January 12, 2010. As of July 2010, all ACE Centers and Networks had submitted data to NDAR during at least one submission cycle.

Ten ACE investigators reported experience with submitting data to NDAR. Of these, half reported that submitting data to NDAR was labor intensive. A few of the investigators also reported confusion (about how the data will be used; what needs to be submitted and when) (3), startup problems (2), or problems with execution (2). Four investigators expressed concern about the potential usefulness of the data format, one expressed concern about early data release, and another expressed concern about privacy issues. Most ACE Program Officers (POs) reported that they have not received reports of any problems with NDAR from their investigators, although three stated that they perceived some anxiety or concern about submitting data to NDAR. Three stakeholder organizations plan to contribute data to NDAR or encourage their funded researchers to do so.

ACE investigators' suggestions for improving NDAR's policies and procedures included: provide funding for data managers; involve investigators in decisions about which data are important; improve the execution of the NDAR contract; don't require data submission before study completion; have more quality control; have an easier coding system; and resolve security issues. POs offered the following suggestions for improving NDAR: create an understanding environment where issues can be freely brought up; listen to the PIs concerns/issues; provide frequent training sessions and additional help features; and provide new tools to analyze data.

Nine of 15 investigators who spoke about NDAR believe that NDAR and its policies and procedures will positively affect data-sharing among investigators and between institutions in the future. One investigator believes NDAR will not affect data sharing. Five investigators expressed uncertainty, primarily because NDAR is so new. Likewise, half of the POs believe that NDAR will positively affect data-sharing and the other half are uncertain. They believe data sharing is important and are hopeful that NDAR will enhance data sharing, but believe it is too early to expect to see results.

ACE Publications and Research Advances – Updated in April 2012 (updated text below in red)

Because the ACE centers and networks were funded in 2007-2008, many of the ACE studies were not yet completed by 2009. However, some early results were available. In the 2008-2009 period, 80 publications were associated with the ACE program. Of these 80 publications, 60 were research articles, 10 were review articles, and the remaining articles were conference papers, editorials, and notes. The ACE program publications appeared in 52 separate journals, with no one journal accounting for more than 7 articles.⁵

Several publications associated with the ACE centers were identified by NIH institutes and centers as science advances. The majority of these advances were related to the genetics of autism. For example,

⁵ The Journal of Autism and Developmental Disorders was the most common journal for the ACE related publications, with 7 articles. This journal was also the most common journal for ACE investigators as a group throughout their careers.

one advance represented a successful application of the genome-wide association study (GWAS) approach to identification of common genetic susceptibility alleles; the results pointed to the importance of genes that are involved in forming and maintaining the connections between brain cells. Similarly, of the 10 articles with the most citations at the close of 2009, 7 were related to the genetics of autism (although two of these were review articles).

In 2010-2011, publications by the ACE centers continued at a similar pace. In 2010, an additional 46 publications credited the ACE centers, and in 2011 an additional 28 publications credited the ACE centers. (The 2011 data are likely to be incomplete, because there is often a lag between the time an article is published and the time it is entered into Scopus, PubMed and other databases.) A wide variety of journals published ACE research—a total of 57 journals were included. As was the case in 2008-2009, the *Journal of Autism and Developmental Disorders* was the most common journal for the ACE related publications. The distribution of articles was somewhat different the prior period, with a smaller number of reviews (9 of 74) included.

Several advances were identified by the NIH ACE institutes and the Interagency Autism Coordinating Committee from this group of publications. As in 2009, many of these advances concerned the genetics of autism. However, several advances also related to improving diagnostic criteria and diagnosing autism as early as possible, and developing new interventions for children with ASDs.

Future Evaluation of the ACE Program

The ACE program feasibility study was conducted to inform the design of future evaluations and to determine whether the suggested evaluation questions, methods, and data sources proposed by the AEIO Working Group are feasible. Both the *Combating Autism Act* and the *NIH Reform Act* of 2006 require NIH to conduct periodic reviews of the ACE Program, although the nature of this review is not stated. A process evaluation that includes consideration of program outputs and short-range outcomes could provide important support for the ongoing

management and oversight of the ACE program. Questions that could be considered for an ACE Program evaluation in the future, building on this feasibility study, are listed in Exhibit 9.

Exhibit 9 *Evaluation Questions for an ACE Program Process Evaluation*

1. What research topics, areas of research and types of autism spectrum disorders (ASD) have been addressed by the ACE Centers and Networks?
2. What publications and research advances have resulted so far from the ACE program?
3. Has the structure and organization of the ACE program provided opportunities for interaction and communication within and across the ACEs?
4. Since the establishment of the ACE program, how many subsequent applications have been submitted to NIH by ACE investigators?
5. Has the ACE program attracted experienced researchers from other fields to ASD research?
6. Has the ACE program attracted (post-doctoral) trainees and young (new) investigators to ASD research?

Components of a process evaluation are described in Exhibit 10.

Exhibit 10: Description of the Major Evaluation Components

EVALUATION COMPONENT	DESCRIPTION
Program Document Review and Data Abstraction	Expanding the baseline data collected during the feasibility study by adding information from later APRs and various NIH databases.
Interviews with ACE Research Investigators and Key Personnel	One-time, semi-structured telephone interviews with ACE investigators including ACE Center PIs, ACE Network PIs, and Network site investigators. Additional interviews could also be conducted with research staff members who are responsible for dissemination and outreach activities and data managers who coordinate data submissions to NDAR.
Interviews with ASD Stakeholder Organizations and Groups	One-time, semi-structured telephone interviews with representatives from stakeholder organizations and groups. The organizations and groups interviewed will be drawn from both national and local organizations with which the ACE Centers and Networks have been involved.
Bibliometric Analysis	An analysis of the scientific research articles published by members of the ACE Centers and Networks, including publication counts, co-author analysis, journal impact factors, citation rates, and the distribution of the program publication research areas with respect to the priorities of the IACC Strategic Plan and the broader NIH ASD research portfolio. Publications will also be used as a source for identifying research advances.

Data Collection Sources and Methods

Data sources for the process evaluation include the following:

- Existing data contained in APRs and NIH administrative databases (IMPAC II/QVR, e-SPA, RCDC, and financial data);
- New data collection, including:
 - Interviews with research investigators at the ACE Centers and Networks (Center PIs, Network PIs, Network site investigators and other key personnel);
 - Interviews with representatives from ASD organizations and groups; and
 - Bibliometric analysis of research publications.

Data collected for the Program Document Review will be collected from APRs and from several NIH administrative databases. This information will update information gathered from the feasibility study. Similarly, publication and grant submission data will be collected for comparison with the baseline data from the feasibility study.

Data from semi-structured telephone interviews with the ACE investigators and key personnel will be obtained. The interviews will focus on progress that has occurred since the baseline interviews conducted for the feasibility study. Data for the bibliometric analysis will be obtained as part of the Program Document Review and will include the scientific research articles published by members of the ACE Centers and Networks.

Given the unique nature of the ACE program, it is not possible to compare the program against other NIH programs. The small number of ACE Centers and Networks means that it is not feasible to use multivariate statistical methods with the data from this study. Similar to the feasibility study findings the basic analytic approach will use descriptive statistics and qualitative analysis to describe what the program has accomplished and how it has changed over time.