



AUTISM SPECTRUM DISORDER RESEARCH PUBLICATIONS ANALYSIS: THE GLOBAL LANDSCAPE OF AUTISM RESEARCH

Prepared by the Office of Autism Research Coordination and Thomson Reuters, Inc.
on behalf of the Interagency Autism Coordinating Committee

July 2012

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CONTENTS

EXECUTIVE SUMMARY	1
INTRODUCTION	5
The Interagency Autism Coordinating Committee: Mission and Strategic Plan	5
Examining autism research publications	8
Rationale for this study	8
Research methods: Identifying and describing autism-related research publications	9
CHAPTER ONE: TRENDS IN AUTISM RESEARCH TOPICS AND PUBLICATIONS	11
What research themes are prominent in autism publications?	12
How were 2010 publications distributed across <i>IACC Strategic Plan</i> Critical Question areas?	12
How much has autism research grown?	13
Which Critical Question research areas are showing the strongest growth?	16
Main findings from analysis of trends in autism research topics and publications	18
SPOTLIGHT ON RISK FACTOR RESEARCH	19
SPOTLIGHT ON TREATMENTS AND INTERVENTIONS RESEARCH	21
CHAPTER TWO: IMPACT AND MATURITY OF THE AUTISM RESEARCH FIELD	25
What is the impact of autism research publications?	25
How is the field of autism research maturing?	27
Main findings from analysis of impact and maturity of the autism research field	28
CHAPTER THREE: GLOBAL AUTISM RESEARCH FUNDERS	29
Who funded autism research in 2010?	29
What is the extent of overlap between funding sources?	32
Do different funder types support different areas of autism research?	33
Main findings from analysis of global autism research funders	35
CHAPTER FOUR: GLOBAL AUTISM PUBLICATIONS AND COLLABORATIONS	37
Which countries are actively engaged in autism research?	38
Are international collaborations increasing and do they result in higher impact research?	43
Which research institutions are publishing the most research?	46
Do institutional collaborations result in higher impact research?	46
Which US states are publishing autism research?	48
Are US researchers engaging in more institutional and international collaboration?	48
Main findings from analysis of global autism publications and collaborations	50
CONCLUSION	51
REFERENCES	54

continued

ABBREVIATED APPENDICES	55
Appendix I: Methodology for Identifying ASD-Related Research Publications and Supplemental Primary Research Publication Counts.....	55
Appendix II: Automated Categorization of ASD Publications (1980-2009).....	63
Appendix III: Web of Science® Journal Subject Categories	64
Appendix IV: Web of Science® Citation Data	65
Appendix V: Full Funder List for 2010 ASD Publications.....	65
Appendix VI: Country Co-Authorship Pairs in 2010 ASD Publications.....	65
Appendix VII: 2010 ASD Publication Counts by Country	65
Appendix VIII: Methodology for Calculating World Share of Autism Research Publications	66
INTERAGENCY AUTISM COORDINATING COMMITTEE MEMBER ROSTER	67
OFFICE OF AUTISM RESEARCH COORDINATION STAFF	69
THOMSON REUTERS STAFF	70

LIST OF FIGURES

Figure 1. The Seven <i>IACC Strategic Plan</i> Critical Questions and Corresponding Research Areas.....	6
Figure 2. Autism Research Pipeline.....	8
Figure 3. Research Methods Used in the <i>ASD Research Publications Analysis</i>	9
Figure 4. Main Questions Addressed in the <i>ASD Research Publications Analysis Report</i>	10
Figure 5. Autism Publications Word Cloud	12
Figure 6. Distribution of 2010 Primary Research Publications within the Seven Critical Question Areas of the <i>IACC Strategic Plan</i>	13
Figure 7. Growth in ASD-Related Publications, 1980 to 2010.....	14
Figure 8. Growth in ASD Research Publications by Critical Question Area within the <i>IACC Strategic Plan</i> , 1981 to 2010.....	16
Figure 9. Number and Fold Growth of ASD Publications from 2000 to 2010.....	17
Figure 10. Publication Output and Trends in Subcategories of Autism <i>Risk Factor</i> Research.....	19
Figure 11. Publication Output and Trends in Subcategories of Autism <i>Treatments and Interventions</i> Research.....	21
Figure 12. Autism Research Citation Rate from 1980 to 2009.....	26
Figure 13. Impact of Autism Publications Compared to Average Citation Rates in Related Publications, 1995 to 2009.....	26
Figure 14. Proportion of Highly Cited Autism Publications from 1995 to 2009.....	27
Figure 15. Types of US and non-US Funders Acknowledged in 2010 Autism Publications.....	31
Figure 16. Overlap Between Different Types of Funders Acknowledged in 2010 Autism Publications.....	32
Figure 17. Patterns of Strategic Research Emphasis by Type of Funder in 2010 Autism Publications.....	33
Figure 18. Extent of Global Autism Research and International Collaborations in 2010.....	38
Figure 19. Global Growth in Autism Publications by Country, 1980 to 2010.....	41
Figure 20. Author Countries for ASD-Related Publications as a Share of the World Total, 1980 to 2010.....	42
Figure 21. International Autism Publication Collaboration Networks in 1990, 1995, 2000, 2005, and 2010	43
Figure 22. Extent of International Collaboration in Autism Research, 1980 to 2010.....	44
Figure 23. Impact of Collaborative International Autism Publications, 1995 to 2009.....	45
Figure 24. Impact of Collaborative Publications with Authors from Multiple Institutions, 2000 to 2010.....	46
Figure 25. State by State Number of US Autism Publications in 2010.....	48
Figure 26. Extent of Institutional and International Collaboration in US Autism Research, 1980 to 2010	49
Figure A-27. Growth in ASD Primary Research Publications by Critical Question Area, 1981 to 2010	56
Figure A-28. Number and Fold Growth of ASD Primary Research Publications from 2000 to 2010.....	57
Figure A-29. Primary Research Publication Output and Trends in Subcategories of Autism <i>Risk Factor</i> Research.....	58
Figure A-30. Primary Research Publication Output and Trends in Subcategories of Autism <i>Treatments and Interventions</i> Research.....	59

LIST OF TABLES

Table 1. 2010 Funders Acknowledged on 10 or More Publications.....	30
Table 2. Top 25 Countries Publishing Autism Research in 2010.....	40
Table 3. Top 25 Institutions Publishing Autism Research Globally in 2010.....	47
Table A-4. Web of Science® and MEDLINE Article Types Classified as Secondary Articles.....	60
Table A-5. Journals in which All Publications Were Classified as Secondary Research.....	61
Table A-6. Comparison Group: Journal Subject Categories Comprising 75% of ASD Publications Since 1980	64

EXECUTIVE SUMMARY

Planning and investment in autism spectrum disorder (ASD) research should be guided by clear objectives that account for the current state of the science and the identification of critical research gaps. Under the direction of the Interagency Autism Coordinating Committee (IACC), this inaugural *Autism Spectrum Disorder Research Publications Analysis Report* describes several key aspects of and trends related to ASD research publications, which can be used to inform planning and strategic funding decisions for future autism research. The IACC is a US Federal advisory committee charged with coordinating all efforts relating to ASD within the US Department of Health and Human Services (HHS). As part of this charge, the IACC is responsible for developing and annually updating a strategic plan for autism research that outlines critical research goals and highlights areas in need of further study and resources. This report reviews the state of ASD research through an evaluation of ASD-related research articles published between 1980 and 2010 and indexed in the Thomson Reuters ScienceWire™ Publication Catalog, and identifies historical trends and publication outputs across the seven critical research areas of the *IACC Strategic Plan for Autism Spectrum Disorder Research*.

Employing an automated categorization methodology customized for this analysis, publications were grouped by how closely they aligned with a single *IACC Strategic Plan* research area. Information found in research publications was also used to identify the institutions conducting ASD research, funding organizations supporting the research publications, and the extent of collaboration between authors from different countries and research institutions. Retrieval of publication data from the ScienceWire™ Publication Catalog provided bibliometric measures, such as citation counts that serve as an assessment of the impact of this published research. While the analyses included in this study are preliminary, and further, more statistically rigorous analyses could be conducted, the results described in this report serve as an indicator of possible trends that can provide a useful perspective on the development and current state of autism spectrum disorder research.

The main findings from each chapter are as follows:

Chapter One: Trends in Autism Research Topics and Publications

- Autism research has demonstrated remarkable growth in the last 10 to 15 years, far outpacing research growth in other comparable fields.
- Publication volume in all *IACC Strategic Plan* Critical Question areas has increased in recent years. While the largest proportions of publications address the basic biology of autism, risk factors, and treatments and interventions, smaller areas such as infrastructure and surveillance, lifespan issues, and services research are growing at least as fast.

Chapter Two: Impact and Maturity of the Autism Research Field

- The impact of autism research, as measured by the extent to which research publications are cited as a source of information in subsequent articles, has been consistently increasing in the last 15 years.
- Overall, autism publications are cited more often than publications in comparable research fields.
- Publication volume, impact, and thematic trends suggest that autism is a young but rapidly growing and evolving field.

Spotlights on Risk Factor Research and Treatments and Interventions Research

- Published research on both genetic and environmental risk factors for autism has increased dramatically over the past decade, with the emerging area of epigenetics experiencing a more recent boost in the number of research publications.
- A number of approaches to treatments and interventions for autism have been published, with behavioral interventions comprising the largest portion of autism publications related to treatments and interventions. Strong growth trends are evident in all of the treatment and intervention categories analyzed.

Chapter Three: Global Autism Research Funders

- Articles published in 2010 contained 2,271 funding acknowledgments representing more than 700 unique funders, including many government agencies and private organizations worldwide.
- Funder acknowledgment data suggest that a substantial portion of autism research publications are funded through collaborations between US government, US private, and international government/private funding organizations.
- Only a third of all 2010 autism publications acknowledged a source of funding.
- Absence of comprehensive funding acknowledgments makes it difficult for funders to track and report research progress, and in turn, hampers their ability to demonstrate the value of research to taxpayers, investors, and public stakeholders.
- Efforts should be made by funding agencies, publishers, and research institutions to encourage the research community to acknowledge funders to ensure continued investment in ASD research.

Chapter Four: Global Autism Publications and Collaborations

- In 2010, autism research was published by authors in over 50 countries and more than 1,800 research institutions worldwide.
- Autism research is increasingly global – while US investigators publish the most autism research, followed by the United Kingdom and Canada, the share of autism research from many other countries is increasing at a faster rate.
- The countries with the largest rise in autism publication activity since 2000 include many countries in Asia as well as Poland and Brazil.
- International and institutional collaborations are increasing in the US and abroad, and collaborative ASD publications tend to have higher research impact.

This publications analysis gives unique insight into the productivity of biological, behavioral, biomedical, clinical, educational, social sciences, and health services research communities in addressing autism spectrum disorders over the last 30 years. By analyzing publications as a major output of the autism research field, this report complements the annual *IACC Portfolio Analysis*, which tracks major US inputs or investments into autism research. Using this extensive state-of-the-field knowledge, policymakers, researchers, and community stakeholders can work in concert to track research progress and identify next steps for advancing knowledge about autism, ultimately supporting the development of needed diagnostic tools, interventions, and services to improve the quality of life for people on the autism spectrum.

INTRODUCTION

The Interagency Autism Coordinating Committee: Mission and Strategic Plan

Two decades ago, autism – a developmental disorder appearing in early childhood and characterized by restricted or repetitive behaviors and impairments in language and social communication – was a little known and rarely diagnosed disorder. Today, with an estimated prevalence of 1 in 88 children in the US, autism spectrum disorder (ASD) has become a top national health priority in the US.¹ In addition, growing recognition of the global impact of ASD has stimulated collaborative efforts of government agencies and private organizations worldwide to fund autism research.

Increasing awareness of the impact of ASD on individuals, families, and society, as well as expanding knowledge of the biological underpinnings of ASD, has driven the rapid advancement of ASD research in recent years. Key priorities reflecting the urgent needs of the community include finding ways to (1) diagnose ASD earlier, (2) understand the underlying biology and risk factors associated with ASD, and (3) develop effective treatments, interventions, services and supports that can reduce disability and enhance quality of life for affected individuals and families across the lifespan. With the anticipated large number of children, adolescents, and adults on the

autism spectrum who will be in need of treatments, interventions, and services in the future, as well as supports to assist them in integrating into their communities, the pressing need for scientific insight and breakthrough research across multiple disciplines has never been greater.

To better coordinate US Federal agency efforts addressing the needs of the autism community, Congress enacted the Combating Autism Act (CAA) of 2006 and the Combating Autism Reauthorization Act (CARA) of 2011, establishing and subsequently reauthorizing the Interagency Autism Coordinating Committee (IACC).¹ The IACC, a Federal advisory committee composed of Federal officials representing agencies engaged in autism activities as well as members of the public stakeholder community, is charged with developing and updating annually a strategic plan to guide Federal investments in autism research, monitoring research activities and progress, and communicating information about advances in autism research to Congress and the public. The IACC also provides advice to the Secretary of HHS regarding Federal autism activities and provides a forum for public participation in the dialogue about issues that affect the autism community and the subsequent development of policy to meet community needs.

¹ The Children's Health Act (CHA) of 2000 established an earlier version of the IACC, but the CAA significantly changed the Committee by specifying membership requirements, mandating several activities and functions, and defining the Committee's role in facilitating public dialogue on matters related to ASD.

The *IACC Strategic Plan for Autism Spectrum Disorder Research*, first released in 2009 and updated in 2010 and 2011, is intended to accelerate and inspire research that will improve profoundly the health and well-being of individuals on the autism spectrum across the lifespan as well as serve as a blueprint for Federal activities and public-private partnerships in ASD research. The *IACC Strategic Plan* was developed with extensive input from the public, including self-advocates, parents, advocacy organizations, researchers, educators, service providers, and other

key community stakeholders. This broad input enabled the development of a plan that spans the range of needs across the autism community. The annual updates to the *IACC Strategic Plan* reflect important new advances in the ASD research field as well as emerging areas of opportunity and need. **Figure 1** summarizes the seven research areas and corresponding Critical Questions of the *2011 IACC Strategic Plan*, including the major topics within each.²

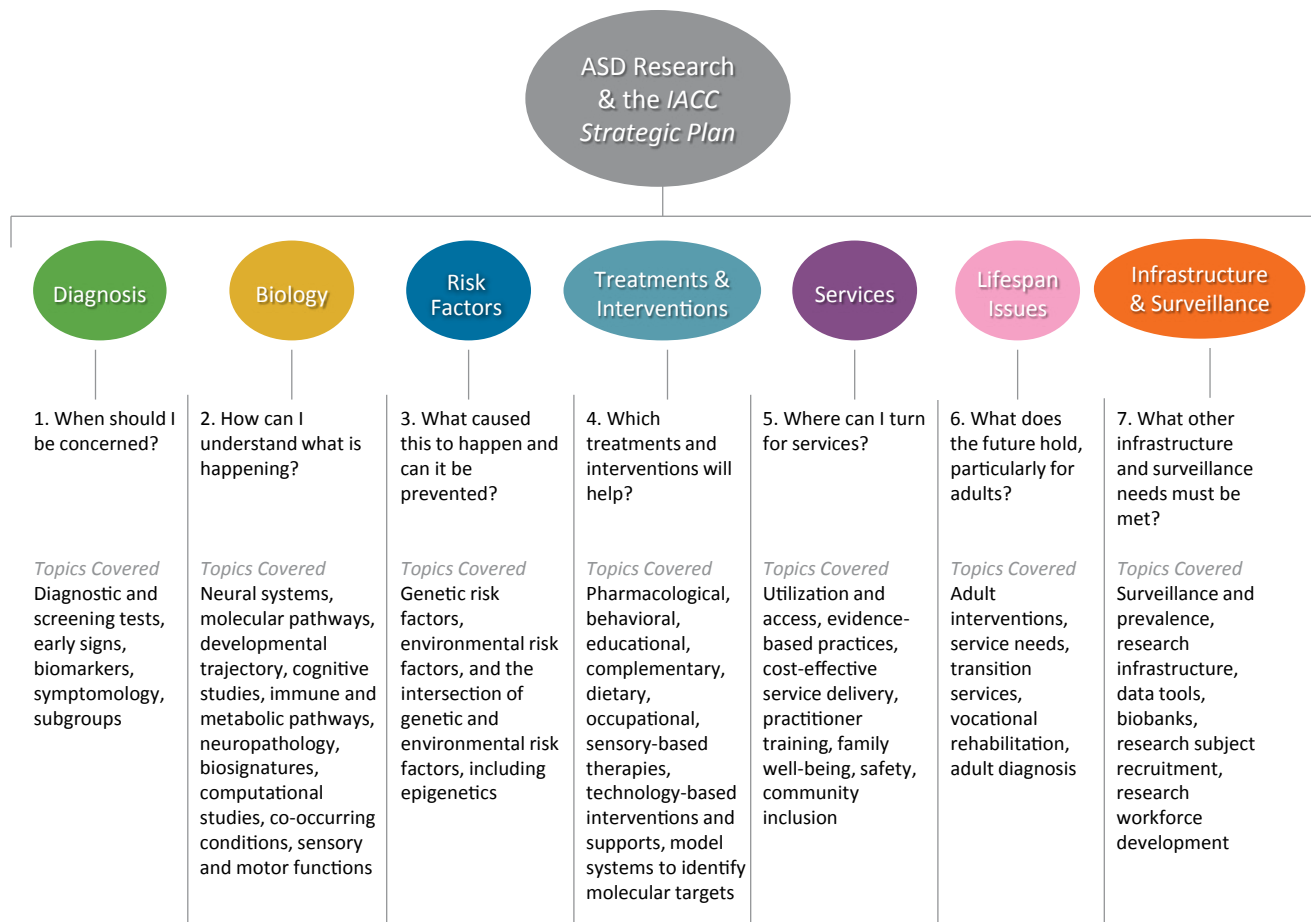


Figure 1. The Seven IACC Strategic Plan Critical Questions and Corresponding Research Areas.

The research areas corresponding to the seven Critical Questions of the *2011 IACC Strategic Plan for ASD Research* are designated in the oval above each question, and a list of topics covered in each section is provided below each Critical Question. The list addresses most of the topics covered within each Critical Question area but is not necessarily comprehensive.

The *IACC Strategic Plan* emphasizes the need for consumer-focused research that addresses the most pressing questions of people and families living with ASD. The needs of the collective autism community are vast and varied and include:

- Recognizing the symptoms and signs of autism early to enable early intervention and maximize potential to reduce disability (*Diagnosis* ●)
- Understanding the biological underpinnings that help explain autism symptoms and can serve as a foundation for research advances (*Biology* ●)
- Identifying genetic and environmental risk factors (*Risk Factors* ●)
- Developing an array of treatments and interventions that are safe and effective for use across the lifespan (*Treatments and Interventions* ●)
- Ensuring that high-quality, evidence-based services and supports are available and accessible to everyone who needs them (*Services* ●)
- Recognizing that autism can result in changing needs and disability throughout life and that research is needed to understand and meet the needs of all people with autism across the lifespan (*Lifespan Issues* ●)
- Developing the infrastructure of the autism research field to coordinate, accelerate, and increase the effectiveness of autism research; and improving autism surveillance efforts to enable more accurate assessment of ASD prevalence in populations in the US and worldwide (*Infrastructure and Surveillance* ●)

Within each of the seven *Strategic Plan* Critical Question areas, the IACC identified numerous specific objectives they believed would advance research, fill key knowledge gaps, and build a foundation for the development of practical tools, interventions, and services to positively impact the lives of people with autism and their families.

The Office of Autism Research Coordination (OARC), an office within the National Institutes of Health (NIH), was established to support the work and mission of the IACC. To assist the IACC in fulfilling its research monitoring function, OARC tracks how US research grants and contracts align with the *IACC Strategic Plan* and publishes these results in the annual *IACC Autism Spectrum Disorder Research Portfolio Analysis Report*. Data from this annual report are used by the IACC to aid in the annual update of the *IACC Strategic Plan* and to inform other activities of the Committee.

While the *Portfolio Analysis Report* has provided a valuable perspective to the IACC on the landscape of research funding across the US, in 2011, the Committee requested that OARC undertake an analysis of ASD research publications in order to provide the Committee with an additional view of the research landscape that could support strategic planning and policy development. Because researchers traditionally publish the results of their work in peer-reviewed research journals, publications serve as a major indicator of research activity.

In response to the IACC's request, and to further aid the Committee in monitoring ASD research and facilitate future strategic planning activities, OARC engaged the expertise of Thomson Reuters, Inc. to collaboratively conduct a comprehensive analysis of research publications relevant to autism. In this *ASD Research Publications Analysis Report*, publications are classified into one of the seven *IACC Strategic Plan* Critical Question areas to determine the volume of research outputs in each area. Publications were also used to collect information about where ASD research is being conducted, which funders are sponsoring the published work, and the extent of collaboration between countries and research institutions.

The *Autism Spectrum Disorder Research Publications Analysis Report* can be viewed as a companion document to the *2010 IACC Autism Spectrum Disorder Research Portfolio Analysis Report*, which provides the most comprehensive account currently available of autism research funding in the United States.³ **Figure 2** illustrates how these reports contribute to a more complete understanding of the ASD research landscape.

Examining autism research publications

Rationale for this study

To inform the IACC and ASD stakeholders of the extent of research activities related to ASD and help identify potential gaps, research publications were analyzed as a measure of research outputs. Publications serve as a particularly rich data source for describing outcomes of funded research,

as they can be used to determine the areas in which research activities are very productive, which institutions are actively engaged in ASD-related research, and which funding agencies are sponsoring the research. Publication data can also be used to identify collaborations between investigators in the field. This is an important metric because studies have shown that collaborations have the potential to yield more fruitful research.^{4,5} While publication volume is a major metric of research outputs, publication traditions differ somewhat across research fields and sectors. For example, social scientists often write books as well as publish in journals – books and book chapters are not well-represented in this publication data set. Additionally, for-profit research efforts in the industrial sector generally result in lower publication rates compared to university and non-profit research activities. Aside from publications, several other key products of research are also good indicators of the extent to which research is being translated

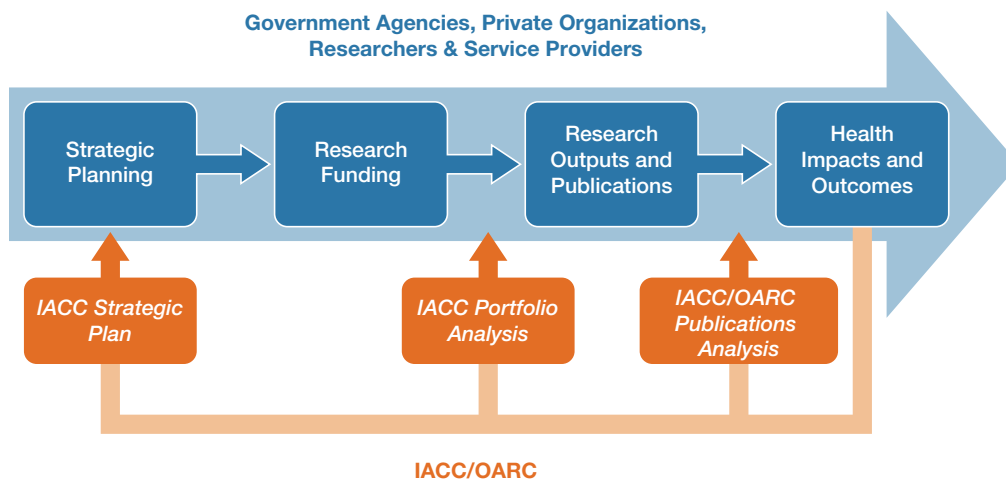


Figure 2. Autism Research Pipeline.

This diagram illustrates the pipeline of autism research inputs and outputs, as well as how various IACC publications inform autism research policy decisions. In the strategic planning process, stakeholders and policymakers identify knowledge gaps and opportunities for research growth. The *IACC Strategic Plan* can be used by funders and researchers to inform their own planning activities and guide research investments, the next step along the pipeline. The *IACC Portfolio Analysis* tracks the portfolio of research grants and contracts from US Federal and private funders, which in turn serves as a valuable tool for strategic planning. Research funding enables novel, focused research leading to new discoveries and expanded knowledge, with publications representing a major research output (see text commentary in the “Rationale for this study” section above for a more complete discussion of research outputs). This *IACC/OARC Publications Analysis* captures the volume and nature of publication outputs, again providing an important tool for planning new research investments. Finally, planning, funding, and knowledge generation in the research realm should result in positive health impacts and outcomes and be informed by health status and needs in the community.

into useful applications. Examples of alternative metrics of research output include patents, policies, curriculum development, clinical trials, Food and Drug Administration (FDA) approvals of new drugs and biological therapeutic products, and inclusion of findings in written guidelines (e.g., operational manuals, healthcare guidelines, and textbooks). Analyses of these alternative metrics for assessing autism research outputs are beyond the scope of this report. However, future attention to these types of metrics would be informative and provide a complement to the information gained through the publications analysis presented here, creating a more complete picture of the autism research enterprise.

Research methods: Identifying and describing autism-related research publications

The methods undertaken for this report are summarized in **Figure 3**. To provide a snapshot of

the autism research landscape from 1980 through 2010, autism-related research publications were identified using the Thomson Reuters ScienceWire™ Publication Catalog database. This database includes research publications from over 11,000 of the world's leading journals since 1900 and covers over 250 disciplines, including areas of social science, education, and humanities in addition to the biological and physical sciences. The breadth of coverage minimizes potential bias towards the biological sciences. Furthermore, ScienceWire™ correlates publication records between Web of Science® and PubMed's MEDLINE databases, providing the most comprehensive citation statistics for bibliometrics alongside Medical Subject Headings (MeSH) terms to facilitate topic analyses.

An automated keyword search was used to identify publications that contained the terms "autism," "autistic," "Asperger," or "pervasive developmental disorder" in the journal title,

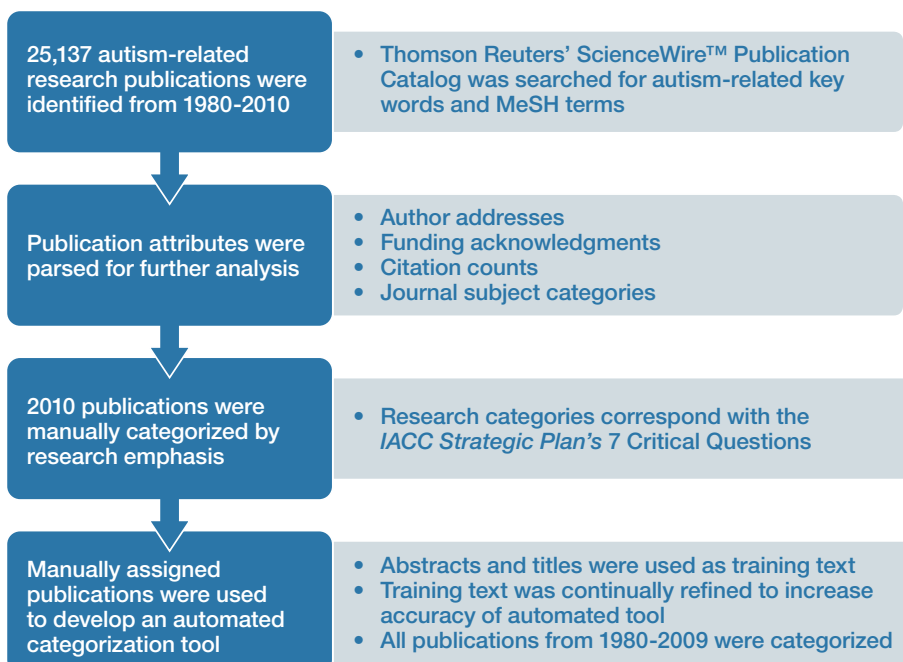


Figure 3.
Research Methods Used in the ASD Research Publications Analysis.

On the left side of this flow diagram, the general research methods used in this analysis are outlined, with additional details for each step explained to the right.

article title, article abstract, or article keywords. Publications tagged with the MEDLINE MeSH terms “Asperger syndrome,” “autistic disorder,” or “child development disorders, pervasive” were also collected. Combined, these processes resulted in 25,137 research publications from 1980 to 2010 being identified as autism-related, 2,477 of which were published in 2010.

These research publications were categorized into primary or secondary literature, with primary publications being defined as articles that contain new and original research findings, including meta-analyses and case reports, and secondary publications defined mainly as reviews and editorials. The specific rules used for separating publications into these two categories can be found in Appendix I.

It is expected that some research publications identified through this automated approach will mention autism-related terms but may not pertain directly to autism research. To estimate the percentage of these false-positive publications, we examined a substantial subset of publications and observed that 1.5% of those identified through the automated keyword search were not directly relevant to autism research. Similarly, it is assumed that a small percentage of research publications that are autism-relevant may be excluded inadvertently from this analysis if they did not contain the designated keywords or MeSH terms. In both instances, the overall impact on the publications sample set is minimal.

Once the publications were collected, titles and abstracts of the papers published in 2010 were manually reviewed and each classified into one of the seven *IACC Strategic Plan* Critical Question areas. Where appropriate, additional text was identified and classified to increase the coverage of research topics in the corpus of training text for an automated classification tool. In total, approximately 4,000 unique texts were manually coded and used to develop the tool, which was then used to classify the remaining publications (1980 – 2009) into an *IACC Strategic Plan* Critical Question area. More than 3,600 publications were reviewed for categorization accuracy, including all 2010 publications and a random set of publications from 1980 to 2009, and we estimate that ~85% of all publications are accurately classified, a relatively high rate of accuracy for an automated analysis (see Appendix II for additional details).

The Thomson Reuters ScienceWire™ database contains rich information on publications it catalogs, including citation data, Journal Impact Factors, Journal Subject Categories, author addresses, and funding acknowledgments. Combining ScienceWire™ publication data with a customized automated approach to classify autism-related articles by their nature of research allows for a highly informative analysis of the global autism research landscape and for a number of key questions (shown in **Figure 4**) to be addressed.

- What autism research topics are being addressed?
- How much has autism research grown?
- What is the impact of autism research publications?
- Who is funding autism research?
- Where is autism research being conducted?
- Is collaborative research increasing in the US and worldwide?

Figure 4. Main Questions Addressed in the ASD Research Publications Analysis Report.

The main questions addressed in the *ASD Publications Analysis Report* were developed to inform the IACC and ASD stakeholders of the historical landscape of autism research as well as emerging trends that can inform future strategic planning and research efforts.

CHAPTER ONE: TRENDS IN AUTISM RESEARCH TOPICS AND PUBLICATIONS

As discussed in the introduction, there are many aspects of autism in need of more research. The research topics of highest priority to the IACC are those set forth in the seven chapters/Critical Questions of the *IACC Strategic Plan* (described in Figure 1). To describe the nature of research being published in autism, publications were classified by how they best aligned with the *IACC Strategic Plan*. First, all 2010 publications were categorized manually into one of the seven Critical Question areas outlined in the *Strategic Plan*. Although some publications naturally span multiple areas of research, each publication was assigned to only one category to facilitate tracking and trend analyses. Given the large number (25,137) of autism-related research articles published in the last 30 years, the results of the manual categorization were used to design a customized automated categorization tool to classify each of 1980-2009 publications into the one most closely matched research category (see Research Methods in the Introduction and Appendix II for more details).

To begin, themes related to each of the Critical Question research areas are described in order to provide a picture of the amount and types of autism research being conducted. Next, the volume and relative proportions of 2010 publications in each of the Critical Question research areas is examined. Finally, results are provided from an analysis of how these research topics and total autism research more generally have grown and evolved over the last 30 years.

identified). The research area with the most primary research publications was *Biology*, followed by *Treatments and Interventions* and then *Risk Factors*. Comparatively less research was published in the *Services*, *Lifespan Issues*, and *Infrastructure and Surveillance* areas. This distribution pattern fits with what is known about several factors that may influence publications in the ASD research field. A discussion of factors that likely contribute to variation in Critical Question area publication output follows at the end of Chapter One in the section, *Which Critical Question research areas are showing the strongest growth?*

How much has autism research grown?

Taking a high-level view of autism research publications across the last 30 years, the overall rate of publication growth was analyzed and publication trends examined for each Critical Question research area. Using the approach described in the Research Methods section, ASD research papers published during the time frame of 1980 through 2010 were identified, and the total number of publications for each year was determined. **Figure 7** shows the total number of ASD publications for each year analyzed (blue line). In 1980, approximately 200 journal articles

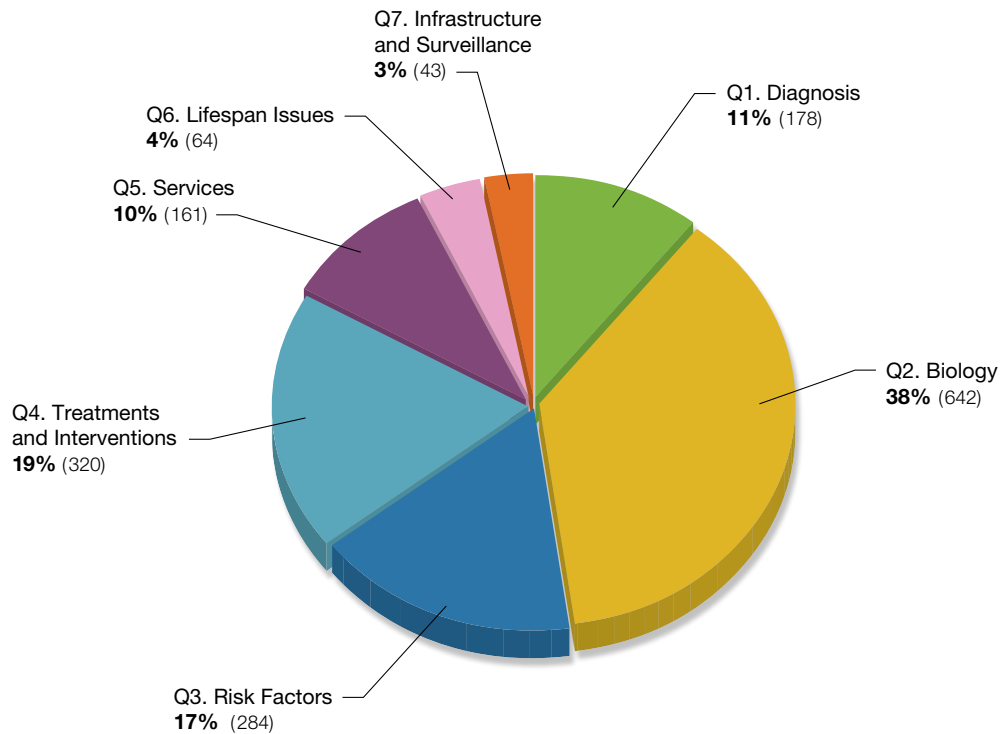


Figure 6. Distribution of 2010 Primary Research Publications within the Seven Critical Question Areas of the IACC Strategic Plan.

The number of primary research publications categorized into each Critical Question area is shown in parentheses and the proportion of total publications is shown as a percentage. The total number of 2010 autism primary research publications with available abstract text for categorization was 1,692. Percentages add up to more than 100% due to rounding.

addressing autism research topics were published. By 2010, the number of autism publications had grown to more than 2,400 per year, representing 12-fold growth in the annual publication output across the last 30 years.

Overall, scientific research output has experienced an upward trajectory for decades. To compare whether the growth of ASD publications from 1980 through 2010 was above or below that of comparable research fields, the growth of ASD research publications was compared to growth observed in all publications included in twelve Web of Science® Journal Subject Categories in which ASD-related articles were most frequently found. The Journal Subject Categories are part of a thematic classification scheme where publications

with similar research topics are grouped together according to the journal in which they were published. Among the 25,137 ASD-related publications collected for the years 1980 to 2010, over 75% fell into twelve Journal Subject Categories: 1) Psychology, Developmental; 2) Psychiatry; 3) Neurosciences; 4) Clinical Neurology; 5) Rehabilitation; 6) Pediatrics; 7) Genetics & Heredity; 8) Education, Special; 9) Psychology, Clinical; 10) Psychology; 11) Behavioral Sciences; and 12) Psychology, Experimental. A similar distribution was also seen for the 2010 ASD publication subset. See Appendix III for the specific breakdown of autism publications into these Journal Subject Categories. The orange line in **Figure 7** represents the number of publications across these broader Journal Subject Categories normalized to the number of ASD-related

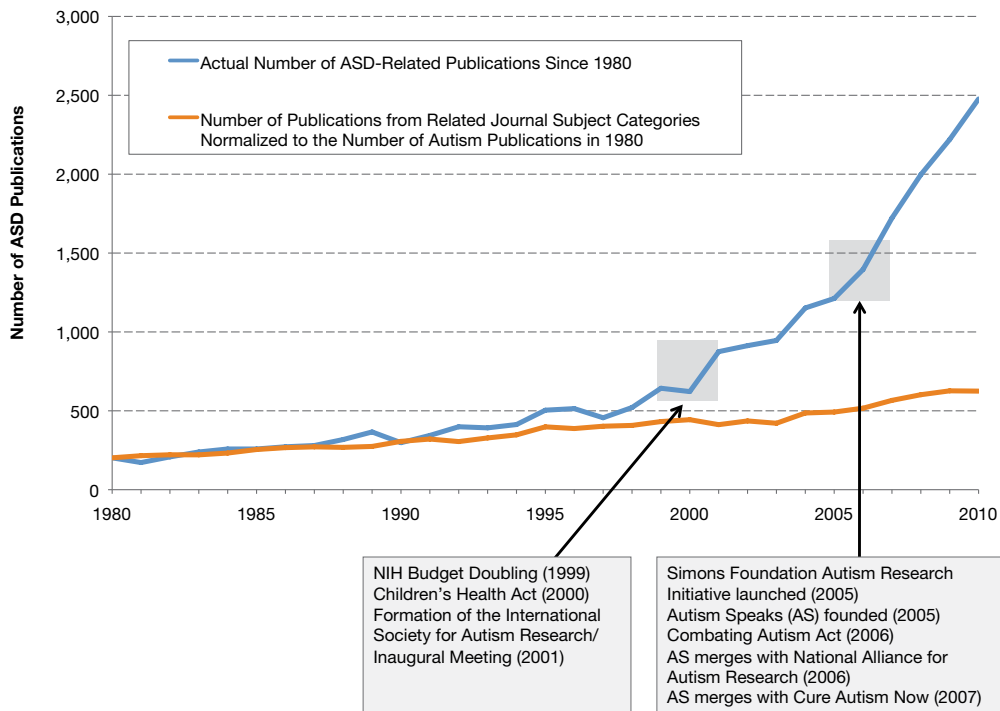


Figure 7. Growth in ASD-related Publications, 1980 to 2010.

The number of autism publications increased dramatically between 1980 and 2010, with a rapid rise in autism research publication rates beginning around 2000 (blue line). The line indicating the expected growth of autism publications in this time frame (orange) is based on a comparison group of publications in the same Journal Subject Categories which comprise over 75% of ASD publications (1980 to 2010). Gray squares highlight the time frames of 1999 to 2001 and 2005 to 2007. Listed below the graph are some of the key events that took place during these time frames. A more complete description of these events is provided in the corresponding text.

publications in 1980 to facilitate the comparison of their relative growths (for a detailed explanation of normalization methodology, see Appendix III). While the ASD publication growth matched the broader publication growth from 1980 to 1998, there has been a sharp increase in ASD publications since 1999, far outpacing the combined growth rate of publications in the 12 related Journal Subject Categories in the same time period.

Growth in the field is likely attributable to increased awareness of and appreciation for the societal impact of autism spectrum disorders. The timeline in **Figure 7** highlights some recent events that may have contributed to the observed growth in autism research, especially in the period from 1999 to 2010. In 1999, Congress began an effort to double the annual budget of the NIH, the largest individual funding source for autism research worldwide. Moreover, the amount of NIH funding devoted to autism-related research projects increased from \$40 million in 1999 to \$169 million in 2011, a more than 4-fold increase.ⁱⁱ

In 2000, the Children's Health Act (CHA) was signed into law, which established an earlier version of the IACC, called for the NIH to establish centers of excellence in autism research, and strengthened Federal autism surveillance activities to track the prevalence of autism across the US.ⁱⁱⁱ In 2001, the International Society for Autism Research (INSAR) was formed to unite autism researchers across many disciplines to accelerate research progress. INSAR held its inaugural scientific conference, the first to be solely dedicated to autism research, in 2001 and now annually convenes almost 2,000 autism

researchers and practitioners from around the world to collectively address the most critical questions in autism research.

In 2006, Congress enacted the Combating Autism Act (CAA) to continue and increase the Federal autism activities set forth by the CHA. In the last decade, several private research foundations and non-profit organizations have also made major contributions to autism research. The Simons Foundation Autism Research Initiative (SFARI) was launched in 2005 and currently provides more than \$50 million a year in autism research grants. Founded in 2005, Autism Speaks became the world's largest autism science and advocacy organization after merging with the National Alliance for Autism Research (NAAR) in 2006 and Cure Autism Now (CAN) in 2007. They fund a broad range of autism research grants annually, including biomedical and services research, and play a critical role in raising support and awareness for autism research worldwide.

ⁱⁱ More information on NIH autism spending can be found at report.nih.gov/categorical_spending.aspx.

ⁱⁱⁱ Following the Children's Health Act of 2000, CDC's newly-established National Center on Birth Defects and Developmental Disabilities established the Autism and Developmental Disabilities Monitoring (ADDM) Network.

Which Critical Question research areas are showing the strongest growth?

The automated categorization tool was applied to autism journal articles published from 1980 to 2009 to determine the number of publications per year within each Critical Question area of the *IACC Strategic Plan* (see **Figure 1** for a description of the Critical Question areas and related research topics). **Figure 8** shows 5-year averages plotted from 1981 to 2010 for each Critical Question area. In general, the trends in the distribution of publications among the seven Critical Question research areas have remained consistent since the 1980s. Research focused on the underlying *Biology* of autism has consistently accounted for the largest segment of publications,

followed by research on *Treatments and Interventions* and *Risk Factors*. Through the years, *Lifespan Issues* and *Infrastructure and Surveillance* have been the research areas with the smallest number of associated articles.

This distribution of research publications across the seven Critical Question areas mirrors the distribution of research funding across these areas as identified by the *2008, 2009, and 2010 IACC ASD Research Portfolio Analysis Reports*.^{6,7,8} For example, *Biology* was expected to have the greatest concentration of research publications because data presented in the annual *IACC Portfolio Analysis* has shown this area to be one of the largest areas of funder investment in recent years. The greater number of publications in this area may also be indicative of the relatively early

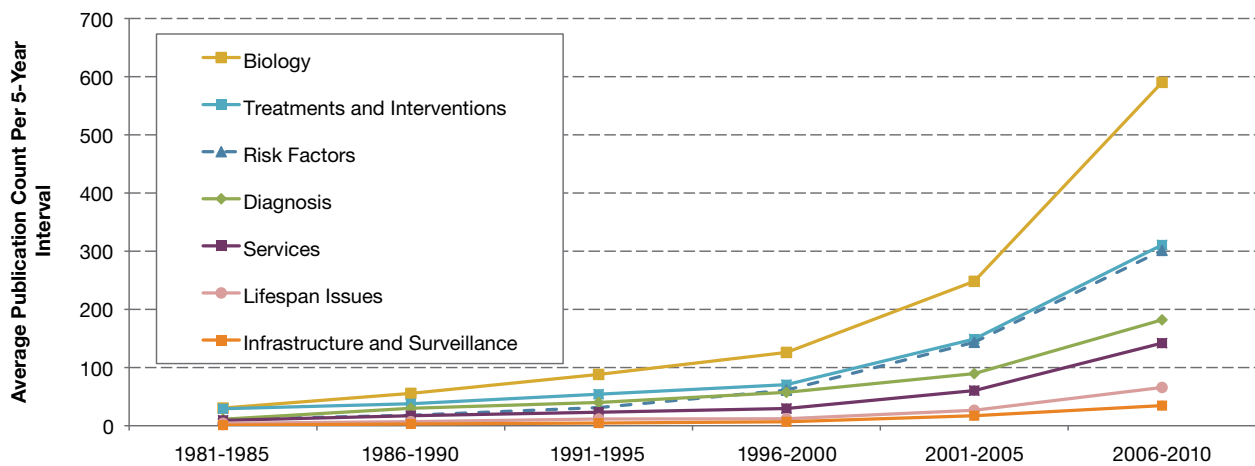


Figure 8. Growth in ASD Research Publications by Critical Question Area within the IACC Strategic Plan, 1981 to 2010.

The growth trends in the Critical Question areas of autism research over the past 30 years illustrate that *Biology* has long been a strong component of autism research, followed by *Treatments and Interventions* and *Risk Factors*. Each data point represents a five-year average of the number of annual autism publications. Publications in this figure include both primary and secondary research. See Figure A-27 in Appendix I for publication output by primary research only.

stage of development of the autism research field, as a strong emphasis on research to understand the underlying biology of diseases and disorders can result in foundational discoveries necessary to support and inform research in more clinical and translational scientific areas such as *Diagnosis* and *Treatments and Interventions*.

The relative differences observed in publication output between the Critical Question areas can be explained partly by the cultures of different research disciplines. For example, basic biological and biomedical research tends to emphasize publication of data as a measure of success, whereas some research in the *Services* area, which may include topics such as assessment of new services, practitioner training approaches, or evidence dissemination efforts, is less likely to

be published in research journals. Certain other Critical Question areas were also expected to have less research activity, including *Lifespan Issues*, which includes a focused subset of biomedical and services research relevant specifically to adults on the spectrum. The proportion of publications in *Infrastructure and Surveillance* was also likely to be small because most infrastructure investments, such as research facilities and training programs, result in publications better classified in one of the other research categories rather than in “infrastructure.” Most of the publications in the *Infrastructure and Surveillance* research area are related to ASD surveillance.

Recent Critical Question growth trends were examined in greater detail. **Figure 9** (top left) shows the annual volume of research publications in each

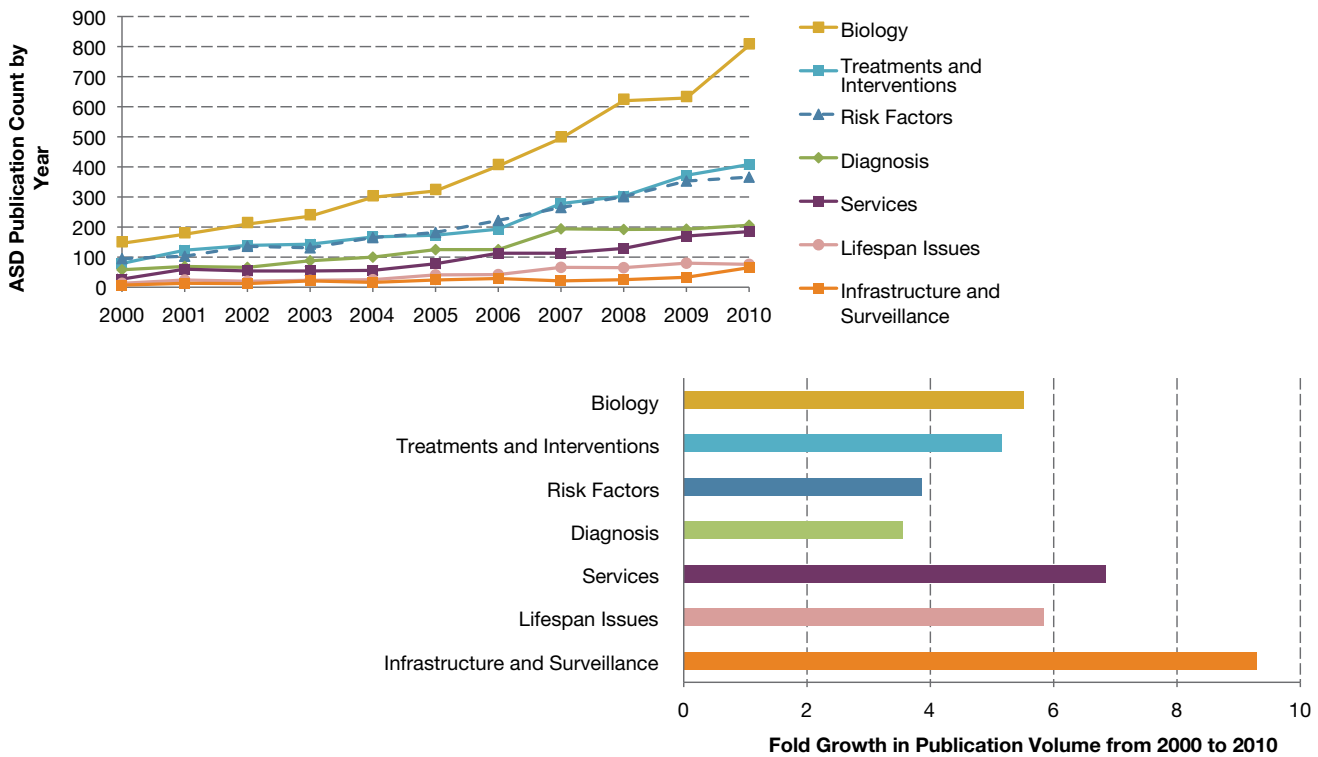


Figure 9. Number and Fold Growth of ASD Publications from 2000 to 2010.

This figure illustrates number (top left) and fold growth (bottom right) of research publications within the respective strategic areas since 2000. Recent growth trends in strategic areas of autism research show that while *Biology* maintains the largest proportion of publications, other areas are growing at least as quickly, including *Infrastructure and Surveillance*, *Services*, and *Lifespan Issues*. Publications in this figure include both primary and secondary research. See Figure A-28 in Appendix I for publication output and fold growth by primary research only.

Critical Question area since 2000, the year in which the autism publication rate began to dramatically increase. **Figure 9** (bottom right) shows the overall growth rate since the year 2000, depicted as fold growth. While *Biology* has the largest proportion of publications each year and has demonstrated substantial fold growth from 2000 to 2010, the smaller categories of *Infrastructure and Surveillance*, *Services*, and *Lifespan Issues* have grown at least as much since 2000. Statistical analyses were run to determine if any Critical Question growth rates were significantly different from the others. The Critical Question areas with the 3 highest fold growth values—*Infrastructure and Surveillance*, *Services*, and *Lifespan Issues*—grew at significantly faster rates than *Diagnosis* and *Risk Factors* publications but are not statistically different compared to *Biology* or *Treatments and Interventions*. Further investment and focused research are needed to catalyze continued growth in all Critical Question areas.

Main findings from analysis of trends in autism research topics and publications

1. The *IACC Strategic Plan* areas of *Biology*, *Treatments and Interventions*, and *Risk Factors* have the highest number of total publications in each year from 1980 to 2010.
2. The overall number of autism research articles published each year – in all Critical Question areas combined – has grown 12-fold since 1980.
3. The rapid growth in autism research publications since 2000 far outpaces that observed in comparable research fields.
4. All *IACC Strategic Plan* Critical Question areas have demonstrated pronounced growth in rate of publication since 2000, including the areas with the smallest number of publications: *Infrastructure and Surveillance*, *Services*, and *Lifespan Issues*.

SPOTLIGHT ON RISK FACTOR RESEARCH

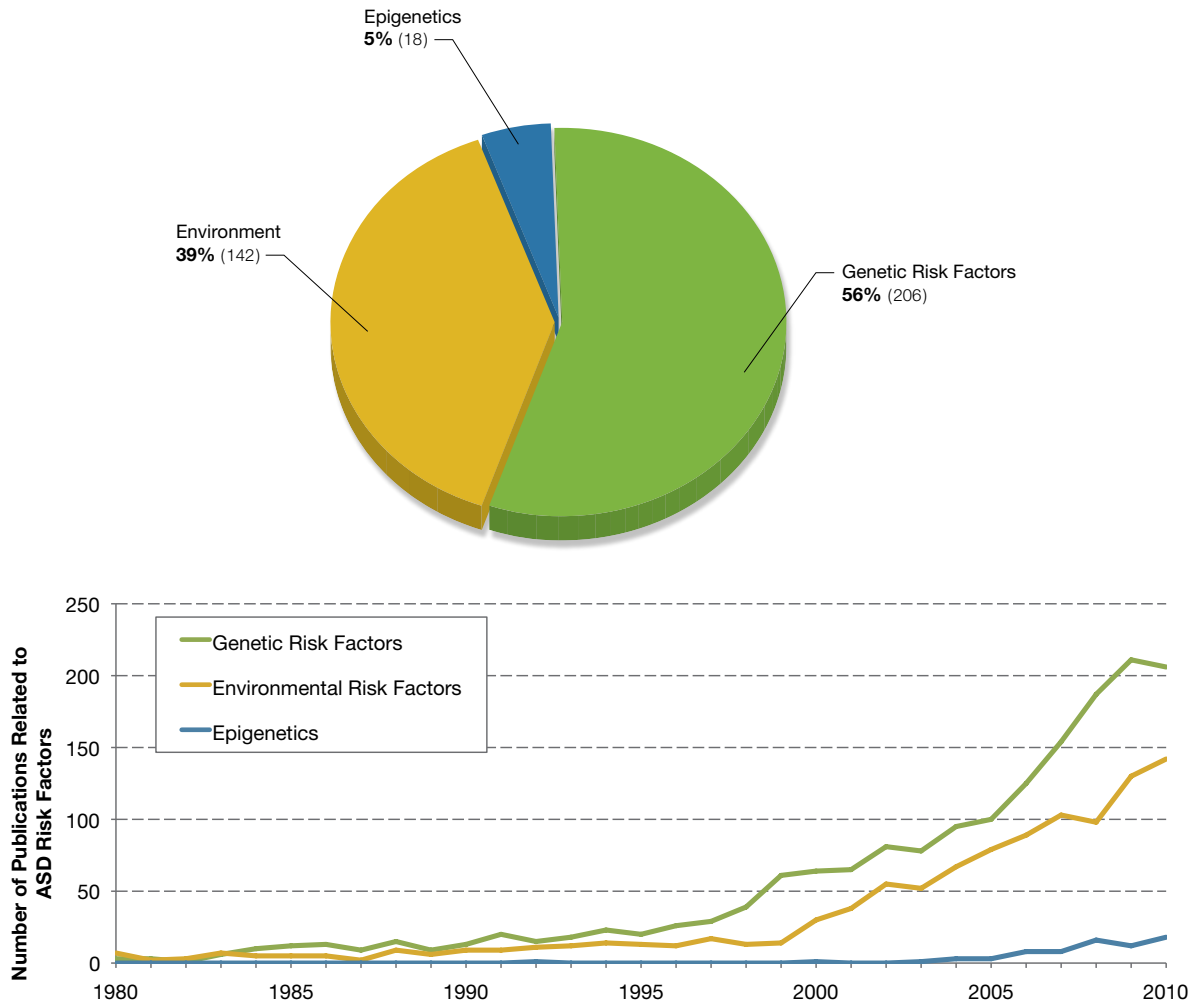


Figure 10. Publication Output and Trends in Subcategories of Autism Risk Factor Research.

The pie graph (top) illustrates relative proportions of research articles published in 2010 in three subcategories of ASD risk factor research and the line graph (bottom) shows the increase in number of publications in each subcategory over time from 1980 to 2010. *Genetic Risk Factors* research had the greatest number and proportion of publications, while the emerging field of *Epigenetics* had the smallest number and proportion of publications. The number of publications in each subcategory has been increasing over time, especially since 1999 for *Genetic Risk Factors* and *Environmental Risk Factors* and since 2006 for *Epigenetics*. Publications in this figure include both primary and secondary research. See Figure A-29 in Appendix I for publication output by primary research only.

With 1 in 88 children affected by autism, the patient and research communities feel a sense of urgency to identify risk factors that may be contributing to the rise in autism prevalence. Autism risk factor research has yielded some strong leads, but much work remains to identify a more complete picture of the

risk factors that play the most significant role in the development of autism. Scientific evidence suggests that genetic and environmental risk factors form a complex web of interactions that determine whether a person develops an autism spectrum disorder.

To provide a clearer picture of research on autism risk factors, risk factor research publications were further classified into three subcategories:

- **Genetic Risk Factors:** This research includes efforts to identify new genes that are implicated in increased risk for ASD or to better understand previously identified genetic risk factors. Since the completion of the human genome map in 2003, scientists have identified a flood of genetic mutations that contribute to a variety of human diseases and disorders, and a few hundred genes have been implicated in autism.^{9,10,11} Some individuals on the autism spectrum have syndromes that result from single gene mutations, such as fragile X, tuberous sclerosis, and Rett syndrome; however, it is estimated that single gene disorders may only account for ~10-20% of all autism cases.¹² The majority of the genetic mutations and alterations identified to date have much more subtle effects, individually accounting for only a small increase in risk.
- **Environmental Risk Factors, including studies on the interaction of genes with the environment:**^{iv} Researchers are actively searching for pre- and postnatal environmental risk factors, either alone or in combination with genetic susceptibility (gene-environment).¹³ Some examples of environmental factors currently being explored in autism risk factor research include maternal dietary factors, maternal medications taken during pregnancy, child and maternal response to immune challenges and infection, environmental contaminants and toxins, as well as social changes in reproductive patterns and parental age. Environmental factors can interact with genetic factors in numerous ways. For example, they can cause novel mutations called *de novo* mutations in parents' germ line DNA.

These molecular events can significantly affect development at various points throughout the lifespan.

- **Epigenetic Processes:** Epigenetics, an emerging area of research, is the study of heritable changes in gene function (such as methylation of DNA) that occur without changes to the DNA sequence. Environmental factors can alter epigenetic processes by affecting the molecules that bind DNA and control gene function. These epigenetic changes can be passed along from one generation to the next and have far-ranging biological consequences, potentially contributing to autism risk.^{14,15}

In this analysis, which includes both primary and secondary research publications, *Genetic Risk Factor* publications comprised the largest share of 2010 publications (56%), followed by *Environment* (39%) and *Epigenetics* (5%). Major upturns in both *Genetic* and *Environmental* research have occurred in the last decade. An appreciable increase in genetics publications can be seen around 1998, and the field has matured since 2000, with large-scale genetics research now commonplace in the autism field. *Environmental Risk Factor* research is somewhat less established, but it has acquired substantial momentum over the last decade. Due to the relative youth of the *Epigenetics* research field in general, research on the role of epigenetics in autism has only emerged in the last few years, and represents a growing area of autism science. Very similar trends were observed when publication output analysis was restricted to primary research publications only. See Figure A-29 in Appendix I for more details. It will be important to continue to track developments in risk factors research to see if current trends continue or new research areas emerge.

^{iv} For the purpose of this report, publications concerning either environment or gene-environment interactions were considered as one category. The categorization algorithm was unable to discriminate accurately between these two related areas. Also, only a relatively small number of these publications specifically address gene by environment interactions (~20 publications in 2010). Please note that in the *2010 IACC ASD Portfolio Analysis Report*, *Environment* and *Gene-Environment* are tracked separately, as these categories are distinguishable when applying a manual coding approach to research grant portfolios.

SPOTLIGHT ON TREATMENTS AND INTERVENTIONS RESEARCH

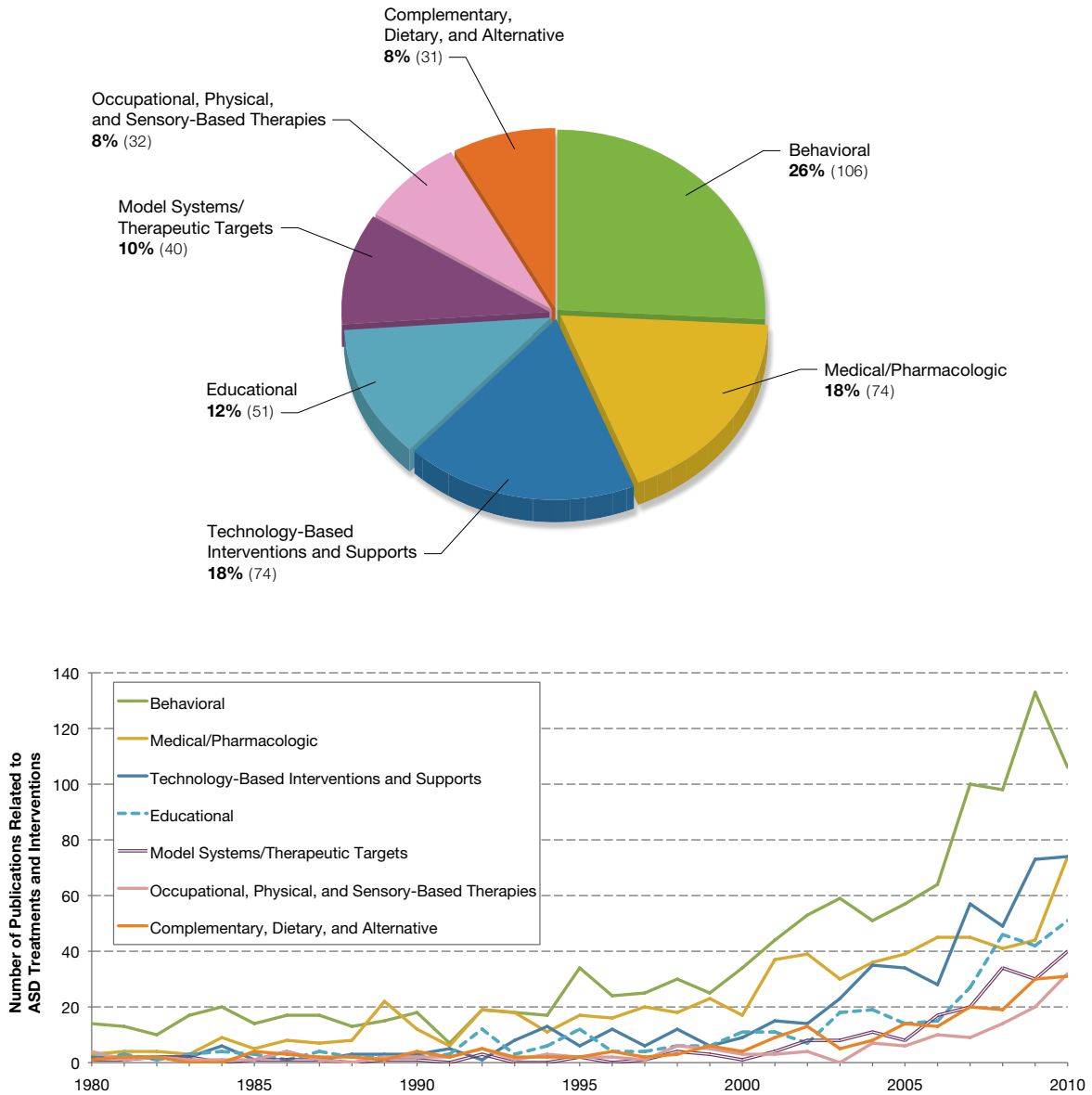


Figure 11. Publication Output and Trends in Subcategories of Autism Treatments and Interventions Research.

The pie graph (top) illustrates relative proportions of research articles published in 2010 on seven subcategories of ASD *Treatments and Interventions* research and the line graph (bottom) shows the change in number of publications in each subcategory over time, from 1980 to 2010. The most prolific areas include research on *Behavioral*, *Medical/Pharmacological*, *Technology-Based Interventions and Supports* and *Educational* interventions. Overall, the number of publications in all subcategories has been increasing since 1999-2000, with a steeper rise beginning in 2005 to 2006. Publications in this figure include both primary and secondary research. See Figure A-30 in Appendix I for publication output by primary research only.

Treatments and Interventions research is one of the highest priority areas for people with autism and their families, as the development of effective treatments and interventions has the potential to reduce disability and significantly enhance quality of life. A wide variety of autism treatment and intervention approaches exist that are designed to reduce disabling symptoms and increase functional skills and abilities, and there is a growing body of research to support the use of particular treatment and intervention approaches. Even so, there is pressing need for a stronger evidence-base across the range of intervention options that are actively used in the home and community. Moreover, researchers are exploring new ways to enhance language skills, communication, and social abilities in people with autism, as well as address the host of medical issues, such as seizures, sleep disorders, and gastrointestinal difficulties, that commonly co-occur with the core features of ASD.

Numerous types of treatment and intervention approaches appearing in the research literature were identified and compiled into one of seven general subcategories that fall under the *Treatments and Interventions* umbrella:

- **Behavioral:** Behavioral intervention research involves a wide array of behavioral therapy and training methods, including applied behavior analysis (ABA), cognitive-behavioral therapy, discrete trial training, Early Start Denver Model, imitation training, joint attention training, Lovaas method, pivotal response training, sibling-mediated interventions, and social skills training.
- **Complementary, Dietary, and Alternative:** Some examples in this group include research on acupressure, acupuncture, antioxidants, cholesterol supplementation, nutritional supplements (e.g., vitamins and minerals), probiotics, and special diets (e.g., gluten-free, casein-free).
- **Educational:** Nearly all ASD research conducted in the classroom falls under this subcategory, including curricula, education methods and best practices, inclusive education programs, math and reading training, positive behavioral supports, special education programs, and other behavioral interventions developed for and tested in educational settings.
- **Medical/Pharmacologic:** This subcategory includes clinical research on drugs (e.g., antidepressants, anticonvulsants, antipsychotics, anxiolytics, hormones, and stimulants) to treat autism and its co-occurring conditions, as well as clinical interventions such as transcranial magnetic stimulation (TMS).
- **Model Systems/Therapeutic Targets:** Research in this subcategory includes the development of animal models that mimic behaviors of ASD, and using animal and cellular models to identify therapeutic targets or test new drug treatments.
- **Occupational, Physical, and Sensory-Based Therapies:** Therapies in this subcategory encompass art therapy, motor training (including fine motor skills such as handwriting as well as gross motor training involving balance and posture), music therapy, occupational therapy, pet (animal) therapy, physical activity plans and exercise therapy (bike riding, swimming), physical therapy, sensory integration, therapeutic horseback riding, training in self-care and daily living skills, and vocational rehabilitation.

- ***Technology-Based Interventions and Supports:*** Augmentative and alternative communication (AAC), computer applications and software, picture exchange communication systems (PECS), social robots, teleconferencing, video modeling, virtual reality (including virtual and 3D environments to mimic social situations), and wearable sensors are all examples of the types of technology in this subcategory of publications.

Publications, which include both primary and secondary research, related to *Behavioral* interventions comprised the largest share of ASD research in 2010 (26%), followed by articles on *Medical/Pharmacological* treatments (18%) and *Technology-Based Interventions and Supports* (18%). In the late 1980s and early 1990s, the two research categories of *Behavioral* and *Medical/Pharmacologic* interventions had approximately equivalent publication counts; however, *Behavioral* intervention research publications experienced a sharp increase around 1999.

Along with the general growth in the autism research field that was catalyzed by many factors, some of which are discussed in Chapter One of this report, many specific advances and events may have contributed additionally to the rapid growth of publications on *Behavioral* interventions during the time frame studied. For example, in 1987, a pivotal publication authored by Ivar Lovaas and colleagues helped establish the Lovaas approach/early intensive behavioral intervention as one of the most used and most effective forms of Applied Behavioral Analysis (ABA) in the treatment of children with autism.¹⁶ In 1999, a key follow-up study by Tristram Smith and colleagues confirmed favorable treatment outcomes and spurred additional research on early intensive behavioral intervention.¹⁷ Also notable, one of the first general ABA treatment manuals was published in 1996, “Behavioral Intervention for Young Children with

Autism: A Manual for Parents and Professionals,” and soon after in 1998, the Behavior Analyst Certification Board (BACB), a certification body for practitioners of ABA, was established.¹⁸

In the last few years, the steepest increase in publication activity among all the research categories has occurred within *Technology-Based Interventions and Supports*. With continuing advances in technology driving this category, this trend will likely continue. The four research areas with the smallest proportion of publications in 2010 – research in *Educational* settings (12%), *Model Systems/Therapeutic Targets* (10%), *Occupational, Physical, and Sensory-Based* (8%) and *Complementary, Dietary, and Alternative* (8%) – all started to demonstrate appreciable growth around 2005, more recently than the larger subcategories. These all appear to be emerging areas of research that may continue to exhibit strong growth in the coming years. Similar publication output trends were observed when the analysis was restricted to primary research articles only. See Figure A-30 in Appendix I for more details.

CHAPTER TWO: IMPACT AND MATURITY OF THE AUTISM RESEARCH FIELD

While the annual numbers of ASD-related publications have grown since 1980, the quality of this research and the maturity of the field remain open questions. The following sections try to address these questions through a variety of measures.

What is the impact of autism research publications?

The “quality” of a research publication is a qualitative assessment that depends on underlying assumptions and values. This analysis focuses instead on several quantitative measures that can provide a more objective assessment of the published research.

The principal bibliometric measure of the impact of a publication within the research arena is the number of times it is cited by other, subsequent publications. When researchers cite published papers resulting from prior research, they are formally crediting the influence of that research on their own work. High citation rates, particularly within a short time after publication, can indicate that an article has a greater impact and influence on subsequent research than articles with lower citation rates.

For the purpose of this study, citations are counted for a period of two years from date of publication. This restriction provides an equitable basis of comparison for all publications from 1980 through 2009, since all have at least two years of subsequent history in which to count citations. Since publishing activity, and thus rate of citation, varies between disciplines and over time, observed citation counts for individual publications can be compared or normalized to the average for related fields, represented here by selected related Journal Subject Categories, and the year in which each paper was published. Both raw and normalized citation counts are used to determine the research impact of ASD-related publications. “Self-citations,” citations from subsequent publications of the author(s) of the original work, are excluded from these measures.

Figure 12 shows that the 2-year citation rate for ASD publications remained fairly flat at approximately one citation per publication from 1980 to 1994, increasing in subsequent years to nearly four citations per publication in 2009. The increase in average citation counts over time may reflect increasing awareness of ASD in the research community and growth of the autism research field. As more research is published in the autism field, more autism publications are cited.

Another way of assessing publication output is to compare autism publication citation counts to the citation rate of related research fields. Focusing on publications from 1995 to 2009, **Figure 13** shows the 2-year average citation counts of autism publications normalized to those in the Journal Subject Category

comparison group (“Average Normalized Citation Count”) published in the same year. A value of 1.0 would indicate that autism citation rates are the same as the comparison group. The normalized citation counts are consistently greater than 1.0 for autism research, peaking at 1.7 in 2009, which indicates that since 1995 autism research has been more highly cited than comparable research fields.

A subset of autism publications is among the most highly-cited research articles within the Journal Subject Category publication set. The proportion of ASD publications that are among this group is another measure of the influence and maturity of the autism research field. **Figure 14** indicates the proportion of autism publications that are among the top 10% of citation counts within the

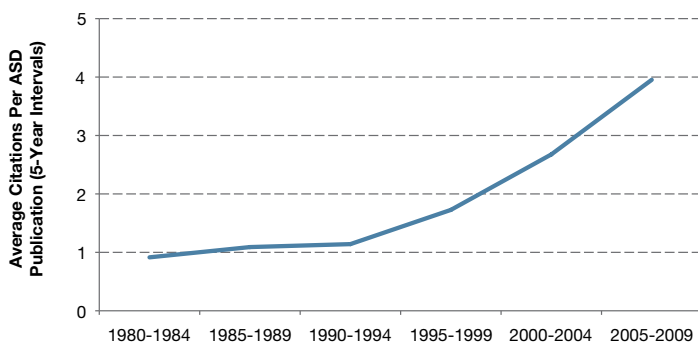


Figure 12 . Autism Research Citation Rate from 1980 to 2009.

The average 2-year citation counts per publication are plotted in 5-year intervals. With the assumption that citation rate can be used as a proxy measure of publication impact, these data suggest that the impact of autism research began to increase after 1994.

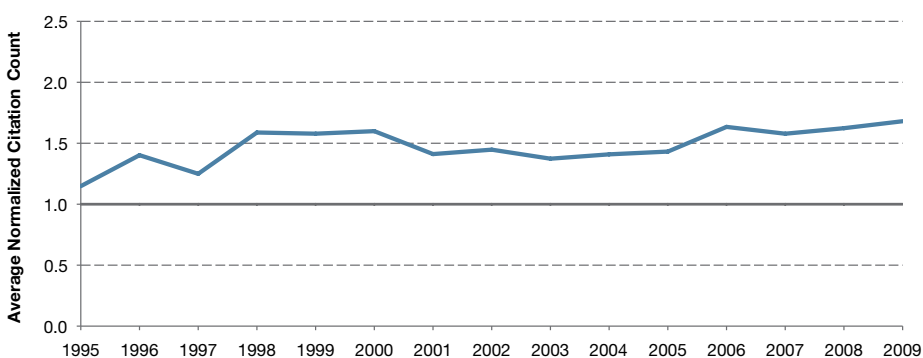


Figure 13. Impact of Autism Publications Compared to Average Citation Rates in Related Publications, 1995 to 2009.

Annual average normalized citation counts are plotted from 1995 to 2009. Citation counts from each ASD publication are divided by the citation rate among all publications of the same Journal Subject Category in Web of Science® in the given year. The average values for ASD publications are consistently higher than 1.0 in each year, indicating a higher citation rate for autism research than the rate in related Journal Subject Categories. This can be interpreted as an indication of the relative high impact of autism research.

Journal Subject Category for each year from 1995 to 2009. While only around 5% of autism research publications were among the most-frequently cited in the mid-nineties, this level has remained consistently between 12% and 15% since 2005. Both that autism publications are well-represented among the most-cited research and that this presence has increased substantially since the 1990s serve as strong indicators of the growing influence of the autism research field and provide evidence that autism research findings are reaching a larger community of researchers.

How is the field of autism research maturing?

Along with the recent remarkable increase in the volume of autism publications produced each year, average citation counts are increasing and more autism articles are among the most highly-cited within their respective fields – all suggesting that the autism field has matured appreciably in the last decade. As a research field matures, one would expect the impact of its publications to increase and for its research findings to be cited by more researchers. Another measure of maturity, especially within biomedical research, is the relative extent of basic science versus translational science outputs.

In Chapter One, the basic *Biology* area was observed to be the largest area of research publications in autism research, which may suggest that autism is still a relatively young research field – a conclusion that is also supported by observation of the publication pattern for the field, which shows few publications prior to 1990, some growth in the 1990s, and a steep rise in growth from 2000 on (Figure 7). It is possible that in future years, there may be growth in or even a shift towards more translational types of research – such as diagnosis, treatments, interventions, and evidence-based services and supports – building on results yielded by more basic areas of study.

Another notable trend demonstrated in the two Spotlight sections on *Risk Factor* research and *Treatments and Interventions* research is that broad scientific innovations are being taken up quickly by the autism research field, notably in the areas of *Genetic Risk Factors* and *Epigenetics*, as well as *Technology-Based Interventions and Supports*. Rapidly changing and emerging fields such as genomics, epigenetics, communication technologies, and robotics are expanding opportunities to develop innovative approaches in autism research.

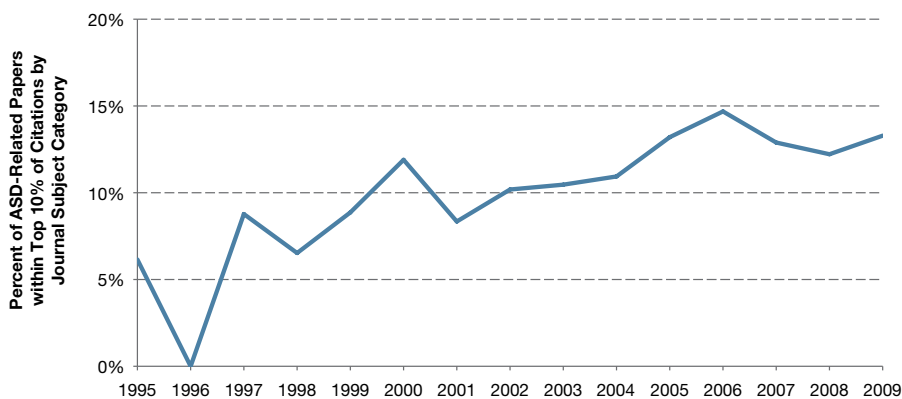


Figure 14. Proportion of Highly Cited Autism Publications from 1995 to 2009.

This graph shows the annual percentage of autism research publications with 2-year citation counts among the top 10% of related Journal Subject Category publications. The proportion of autism publications that reached this high level of citations increased between 1995 and 2009, indicating the growing influence of autism research.

The likely drivers of the growing maturity of the autism field are enhanced public awareness of ASD, the uptake of research techniques and innovations from the broader scientific community, and increased research funding. Several governmental funding bodies, non-profit organizations, and private research foundations worldwide are leading the call for more research and are infusing significant investments into the field. The next chapter provides an analysis of funding acknowledgments from the 2010 autism publications to determine which organizations are funding autism research around the globe.

Main findings from analysis of impact and maturity of the autism research field

1. Current autism research has a higher impact than earlier publications.
2. Work in autism is generally more highly cited than comparable research fields.
3. The proportion of very highly cited articles with an autism research focus has increased since 1995.
4. Publication volume, impact, and thematic trends suggest that autism is a young but rapidly growing and evolving research field encompassing several emerging subfields and influenced by advances in knowledge and technology from other scientific disciplines.

CHAPTER THREE: GLOBAL AUTISM RESEARCH FUNDERS

The 2010 IACC Autism Spectrum Disorder Research Portfolio Analysis Report tracks US public and private autism research funding, or inputs, as shown in **Figure 2**.¹⁹ This chapter of the *ASD Publications Analysis* complements the *IACC Portfolio Analysis* by providing an examination of the publication activity of US and non-US funders to determine which have made significant contributions to published research, or research outputs. Acknowledged funders were identified to reveal prominent funding bodies in the autism research arena. These funding bodies were classified as either governmental or private, and the extent to which publications cited multiple sources of funding was assessed.

Who funded autism research in 2010?

To identify the organizations that sponsor autism research, the text from the funding acknowledgments sections of research publications was obtained for each publication, as available. This was achieved using a variety of strategies. The Web of Science® database includes the complete funding acknowledgment paragraphs for articles published since 2008, and MEDLINE has collected these data for publications acknowledging US NIH funding. A list of known funding organization names and aliases was also used to search the acknowledgment sections to increase the number of funders identified.

While the funding acknowledgment data in these databases are informative, it is important to understand its limitations. Different countries may have different philosophies or guidelines that influence how or when researchers acknowledge funding sources, which may result in fewer acknowledgments in some publications. Journals also have varied policies regarding the formatting and information included in the acknowledgment sections, which may affect the results of automated searches for acknowledgment data. Researchers may also simply overlook the need to acknowledge one or all of their funding sources. Despite these limitations, the funding acknowledgment data collected serve as a valuable resource for analyzing the support for many of the 2010 autism publications.

Among the 2,477 autism research articles published in 2010, 870 (36%) acknowledged a funding source. This percentage is somewhat lower than that determined in a similar analysis, which reported an average funding acknowledgment rate of 43% in all 2009 research publications indexed within Web of Science®.²⁰ Among the 2010 autism publications, the most acknowledged funder was the US National Institutes of Health (NIH) (**Table 1**). NIH may receive more funding acknowledgments compared to other funders, not only because it may support more publications than other funders due to the

	Funding Organization	Country	Funder Type	Publications with acknowledgment
1	National Institutes of Health	US	Government	437
2	Autism Speaks	US	Private	119
3	The Medical Research Council	UK	Government	59
4	European Union	EU	Government	38
5	Wellcome Trust	UK	Private	36
6	The Canadian Institutes of Health Research	Canada	Government	35
7	Simons Foundation	US	Private	27
8	National Science Foundation	US	Government	26
9	Ministry of Education, Science, Sport and Culture	Japan	Government	25
10	Brain and Behavior Research Foundation/NARSAD	US	Private	24
11	Japan Society for the Promotion of Science	Japan	Government	18
12	German Research Foundation (DFG)	Germany	Government	17
13	Netherlands Organization for Scientific Research (NWO)	Netherlands	Government	15
14	Natural Sciences and Engineering Research Council	Canada	Government	14
15	National Institute for Health and Medical Research	France	Government	13
15	Ministry of Education, University and Research	Italy	Government	13
17	Howard Hughes Medical Institute	US	Private	12
17	Nancy Lurie Marks Family Foundation	US	Private	12
19	Centers for Disease Control and Prevention	US	Government	12
19	Federal Ministry of Education and Research	Germany	Government	12
19	FRAXA Research Foundation	US	Private	12
19	Genome Canada	Canada	Private	12
23	Health Research Board	Ireland	Government	11
23	National Institute for Health Research	UK	Government	11
23	Ministry of Health	Italy	Government	11
23	The National Health and Medical Research Council	Australia	Government	11
27	National Science Council	Taiwan	Government	10
27	Swedish Research Council	Sweden	Government	10
27	Ministry of Health, Labour and Welfare	Japan	Government	10
27	Economic and Social Research Council	UK	Government	10

Table 1. 2010 Funders Acknowledged on 10 or More Publications.

Funders are listed along with their country of origin, their type, and the number of publications in which they are acknowledged. In cases where a single publication acknowledges multiple sources, the publication is counted for each source acknowledged.

size of its investment in autism research, but also because of the agency’s requirement that grant recipients acknowledge support in all resulting research publications.^v While it is likely that the overall number of publications attributed to specific funders is underreported, there is a large enough sample of acknowledged funders among the 2010 autism publications to obtain informative details about funders and their activities. Once identified, funders were manually assigned to the following five categories:^{vi}

- a. Government
- b. Private, including non-profit and for-profit organizations
- c. University
- d. Hospital
- e. Public-Private Partnership

Funders were also defined by their country of origin. The complete list of acknowledged funders, categorized by funder type (e.g., Government, Private, etc.) and home country is provided in Appendix V.

More than 700 unique funders were represented among the 870 autism research articles published in 2010 for which funding acknowledgments could be collected. In many cases, more than one funder was acknowledged in a given article. **Table 1** lists those funding organizations cited by 10 or more publications in the 2010 publication set. The most acknowledged funders were from the United States – the NIH, a Federal funding agency, with 437 acknowledgments, and Autism Speaks, a non-profit organization with 119 acknowledgments. The remaining organizations represent a mixture of non-US, governmental, and private funding organizations. Approximately

^v NIH grant policy details can be found at: http://grants.nih.gov/grants/policy/nihgps_2011/index.htm.

^{vi} Description of funder types: 1) Government includes all public funding (i.e., State, Federal, etc.), 2) Private includes non-profit/philanthropic organizations as well as for-profit industry, 3) University includes all universities, public and private, 4) Hospital includes all hospitals, public and private, 5) Public/private partnership includes funding sources that have significant governmental and private support.

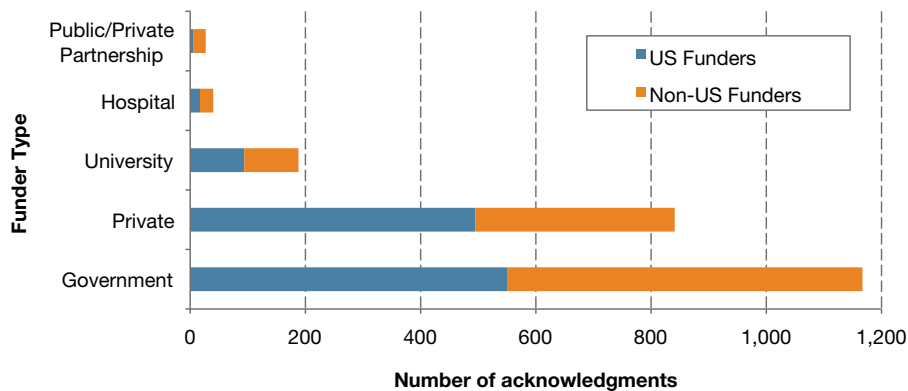


Figure 15. Types of US and non-US Funders Acknowledged in 2010 Autism Publications.

The number of funding acknowledgments is displayed by type, including Government, Private (non-profit and for-profit), University, Hospital, or Public/Private Partnership, and by their country of origin (the number of US funder acknowledgments in blue and non-US funder acknowledgments in orange). In cases where a single publication acknowledges multiple sources, each source is counted individually. Within the 870 publications with funding acknowledgment data, the total number of individual funding acknowledgments was 2,271.

two dozen of the private funding organizations were pharmaceutical companies, which received a combined 45 funding acknowledgments, representing only a small fraction of private funder acknowledgments (~5%).^{vii} Pharmaceutical and other for-profit industries are less likely to support work that is published in peer-reviewed literature; therefore, funding acknowledgment data for these groups are limited.

Overall, the acknowledgments data indicate that ASD research was supported by a wide array of US government agencies and private foundations as well as many non-US organizations, both government and private. **Figure 15** shows the distribution of funder types across all of the 2,271 funding acknowledgments in the 2010 publication set as well as the number of US and non-US funding organizations within each category. While it is not too surprising that government funding agencies were most frequently acknowledged for providing funding support, since government agencies tend to provide a large proportion of overall research funding related to health conditions and may also have strong funding acknowledgment policies, it was of interest to find that private funders were cited nearly as often. This may suggest that private funders also have strong funding acknowledgment policies or are effective in following up with funded researchers to ensure acknowledgment.

Funding acknowledgments were split almost evenly between US and international funders, with US-based funders representing 51% percent of all acknowledgments (1,168 of 2,271) and being acknowledged by 64% of all publications that cited funding (560 of 870). As indicated in Table 1 and Appendix V, funding organizations from

Canada, Europe, Australia, and Asia also account for substantial funding acknowledgments.

What is the extent of overlap between funding sources?

With numerous governmental and private organizations funding autism research, investigators often secure multiple sources of funding to increase their budgetary resources to

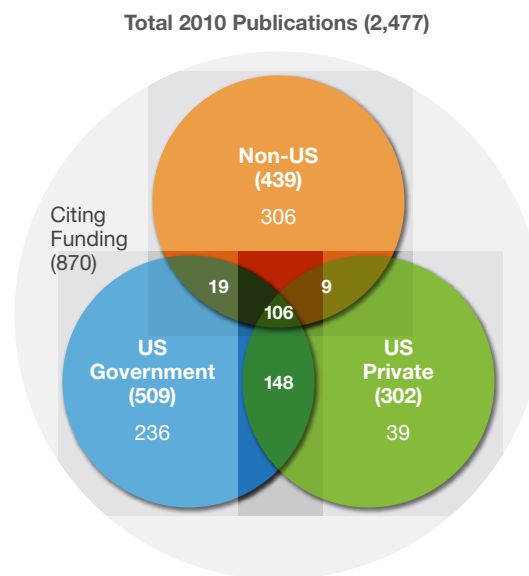


Figure 16. Overlap Between Different Types of Funders Acknowledged in 2010 Autism Publications.

This Venn diagram represents all 2010 ASD publications that acknowledged or cited at least one funding source. The type of funding source was manually categorized into one of three groups: 1) Non-US funders (cited in 439 publications), 2) US government funders (cited in 509 publications), and 3) US private funders (cited in 302 publications).^{viii} Areas of overlap in the diagram indicate publications that cited two or all three of the funder types. For example, in US government cited papers, 236 only cited a US government funding source, 19 publications cited the US government plus a non-US funder, 148 publications cited US government plus a US private funder, and 106 cited all three funding sources.

^{vii} Funding acknowledgments to pharmaceutical companies in the ScienceWire™ database were manually reviewed to determine whether an acknowledgment indicated direct funding support or a general conflict of interest. Acknowledgments that were deemed conflict of interest statements were not included in this analysis.

^{viii} Seven publications only acknowledged funding from hospitals and universities. These are included in the total number of publications with funding acknowledgments (870), but not represented in the Venn diagram.

support their work. To better understand these sources and extent of overlap between multiple funder types supporting the same research, the funding acknowledgments sections of autism-related journals were analyzed. **Figure 16** shows the distribution of the 2010 publication funding acknowledgments among US government, US private, and non-US funding organizations as well as the number of publications shared between two (~20% of all publications) or all three funder types (~13% of all publications).^{ix} More than 30% of the publications (282 of 870) acknowledged funding from a combination of non-US, US government, and/or private sources. These areas of intersection suggest considerable multinational and collaborative efforts related to autism research.

Do different funder types support different areas of autism research?

The Critical Question categorization scheme for publications was used to investigate whether different funder types supported different aspects of autism research. The number of publications linked to each funder type was determined, and publications were then further sorted into one of the seven Critical Question areas identified in the *IACC Strategic Plan for ASD Research*. **Figure 17** compares the degree to which various funder types support studies in the different Critical Question research areas. The predominant pattern is similar for US government funders, US private funders, and non-US funders^x of autism research.

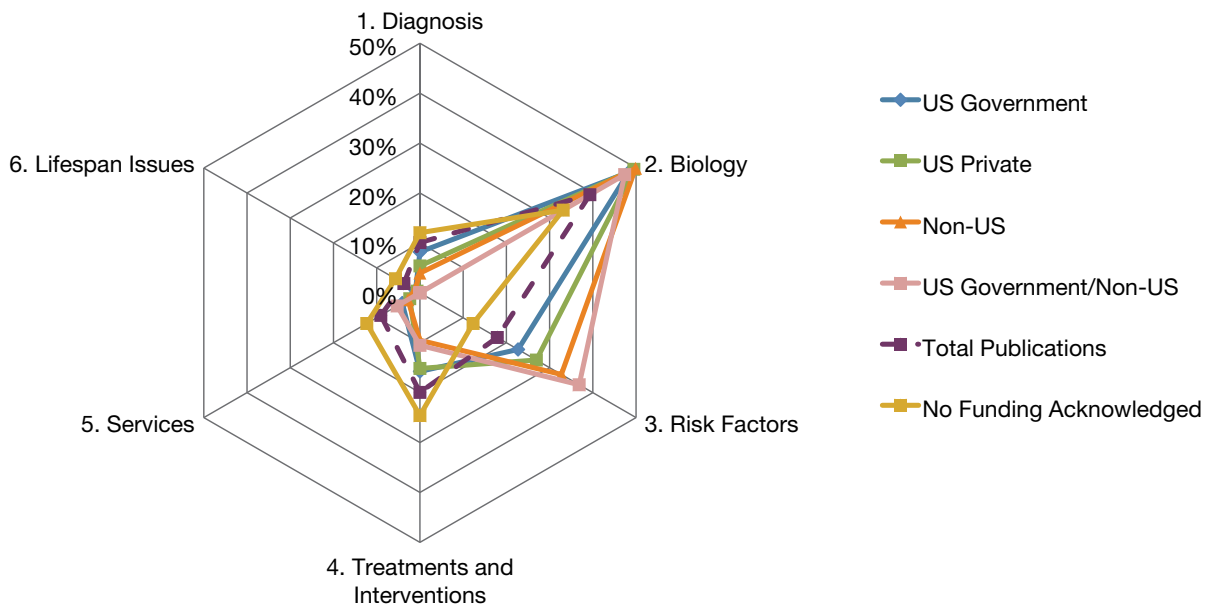


Figure 17. Patterns of Strategic Research Emphasis by Type of Funder in 2010 Autism Publications.

This graph plots the distribution of publications by Critical Question category for all 2010 publications (purple) and the type of funding those publications received, including US government (blue), US private (green), Non-US funders (orange), US government plus Non-US (pink), and publications that did not cite a funding source (gold). The patterns show that publications that received funding from both a US government and a non-US source were relatively more likely to be related to *Risk Factors* than the other funder types, and publications that did not acknowledge a funding source at all were more likely to fall into the categories of *Treatments and Interventions*, *Services*, and *Lifespan Issues* research. For figure clarity, *Infrastructure and Surveillance* publications are not included in this graph because the proportion of *Infrastructure and Surveillance* publications in all groups studied was very low.

^{ix} For ease of analysis and figure clarity, all non-US funders, government and private, were grouped together for funding overlap analyses.

^x This group represents a combination of non-US government and non-US private funders.

The distribution of publications is skewed toward the basic *Biology* of ASD for all of these funder types, followed in order by research on *Risk Factors*, *Treatments and Interventions*, and *Diagnosis*. There were two deviations from this pattern. First, publications supported by international funding in the form of US government plus a non-US funding source show a somewhat higher proportion of publications in the area of *Risk Factors*. With few exceptions, publications with international funding also had international co-authors (described later in this report as “international collaboration”). The specific *Risk Factor* research publications were examined in detail and we found many to be large-scale gene discovery studies collaboratively co-authored by North American and European investigators. A second distinctive pattern of Critical Question distribution was observed in publications that did not acknowledge a funding source. A heavier concentration of these publications was associated with research in the *Treatments and Interventions*, *Services*, and *Lifespan Issues* Critical Question areas.

As noted above, the funding acknowledgment rate of 36% observed for 2010 publications was lower than the overall rate of 43% reported across all publications in Web of Science®.²¹ That same study also showed that funding acknowledgment rates in research publications can vary greatly across different research disciplines with the highest rates of funding acknowledgment – between 55% and 68% – found among publications in the natural sciences (e.g., molecular biology, chemistry, and biological sciences). In contrast, lower rates were observed in clinical medicine (32%), psychology and behavioral science (27%), and social sciences (<10%). These trends are similar to those seen among ASD publication funding acknowledgments. Specifically, in this 2010 autism publications set, articles published in education and social science fields had lower rates of funding acknowledgments than other areas. Even within the *Biology* and *Risk*

Factor Critical Question areas, which had the highest rate of funding acknowledgment at 50% and 60%, respectively, a sizeable portion of the 2010 autism publications did not cite a funding source. While it is possible that research in these areas is being undertaken without formal funding support, a more likely explanation is that researchers are not acknowledging their funding sources, perhaps due to the culture of those fields or to absence of policies to require or encourage funder acknowledgment.

The absence of funding acknowledgments makes it difficult for funders to track and report progress on their investments, in turn making it more challenging for funders to demonstrate return on investment to taxpayers, donors, and investors. As productivity is often used to evaluate the effectiveness of research funding and to provide a rationale for continuing or augmenting funding levels, the inability to attribute research results to a specific funding source for such a large proportion of research publications presents potential loss of opportunities to communicate research progress and stimulate research in the autism field. Given this risk, improving the rate of acknowledgment of funding sources both in the US and internationally is an important issue that needs to be addressed to help ensure continued support and growth of the autism research field.

Although funding acknowledgment data provide a snapshot of international funding and research activity, these data have their limitations, as discussed previously. Non-US funders account for approximately half of all funders acknowledged for supporting 2010 autism research publications, suggesting that global research activity in autism is extensive. For a more comprehensive and accurate account of where autism research is taking place, author address information from the Web of Science® database was used to track global autism research publications and collaborations, which will be discussed in the next chapter.

Main findings from analysis of global autism research funders

1. 2010 ASD publications contained 2,271 funding acknowledgments to more than 700 different funders, including many government agencies and nearly as many private organizations.
2. Approximately one-third of publications with funding acknowledgment data cited some combination of US government, US private, and international funding support.
3. Absence of comprehensive funding acknowledgments in approximately two-thirds of ASD research publications makes it difficult for funders to track and report research progress.
4. Inability of funders to comprehensively track research publications stemming from their investments may result in lost opportunities to communicate progress resulting from these investments and grow the autism field.
5. Given potential risks and lost opportunities arising from a large proportion of research not providing funding acknowledgment, policymakers, funders, publishers, and institutions should encourage the research community to acknowledge research funders to ensure continued investment in ASD research.

CHAPTER FOUR: GLOBAL AUTISM PUBLICATIONS AND COLLABORATIONS

This chapter highlights where autism research is taking place and identifies key trends, including which countries are increasing their share of autism global output, the extent of collaboration between authors in different countries and different research institutions, and whether collaborative research results in higher impact autism publications.

To determine the geographic locations of autism-related research activities, the Web of Science® author address field was used to identify the research institution, country, and US state for each author on a given publication within the ASD publication set. Publications with multiple authors were therefore attributed to multiple addresses. Publications that contained authors from multiple countries were also examined in detail. In this report, “collaboration” refers specifically to occurrences in which researchers from different institutions or different countries co-authored an autism publication. For example, if a publication was attributed to more than one country, country pairs were generated. This kind of co-authorship analysis serves as a general indicator of collaboration, but it does not capture all aspects of collaborative research. In addition, this study used citation count analyses to compare the impact of collaborative publications to those from single institutions or single countries. This provides one measure of

whether multi-institutional and international collaborations are resulting in benefits to ASD research, with the assumption that more highly cited publications are being more widely disseminated and used within the research community.

This preliminary analysis of co-authorship and collaboration was performed in order to understand whether autism research is becoming a more global endeavor, and if so, if this may be beneficial to the field. It is often assumed that collaboration is especially beneficial for an emerging research field, such as autism, potentially providing researchers with access to a larger pool of expertise, participants, and resources than otherwise possible. Other analyses have provided support for the hypothesis that multi-institutional and international co-authorship collaborations can result in higher impact publications.^{22,23,24,25,26} Some exceptions to this trend, however, have also been reported. In particular, studies have shown that extensive geographic distance between co-authors may hamper citation impact in certain fields and in particular time periods.^{27,28} While the current analysis only provides a few targeted measures of collaborative activity, the results may serve as a foundation for further analyses of the implications and impacts of various types of collaboration on autism research.

Which countries are actively engaged in autism research?

Figure 18 is a heat map indicating the concentration of 2010 autism publications by country as well as the number of “collaborations,” or more precisely, the number of times researchers from two countries were listed as authors on the same paper. The US, shaded in the darkest color of blue, had the

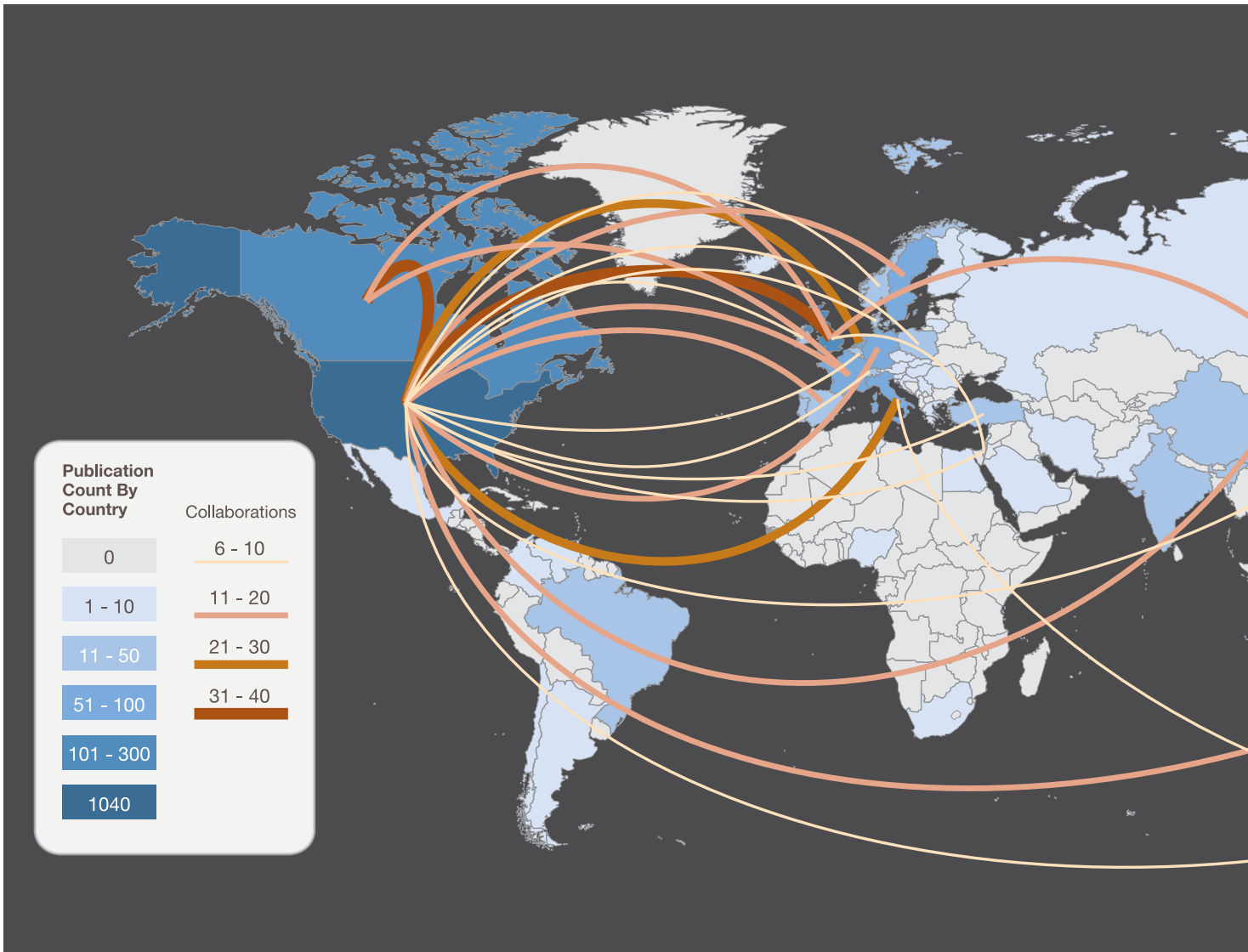
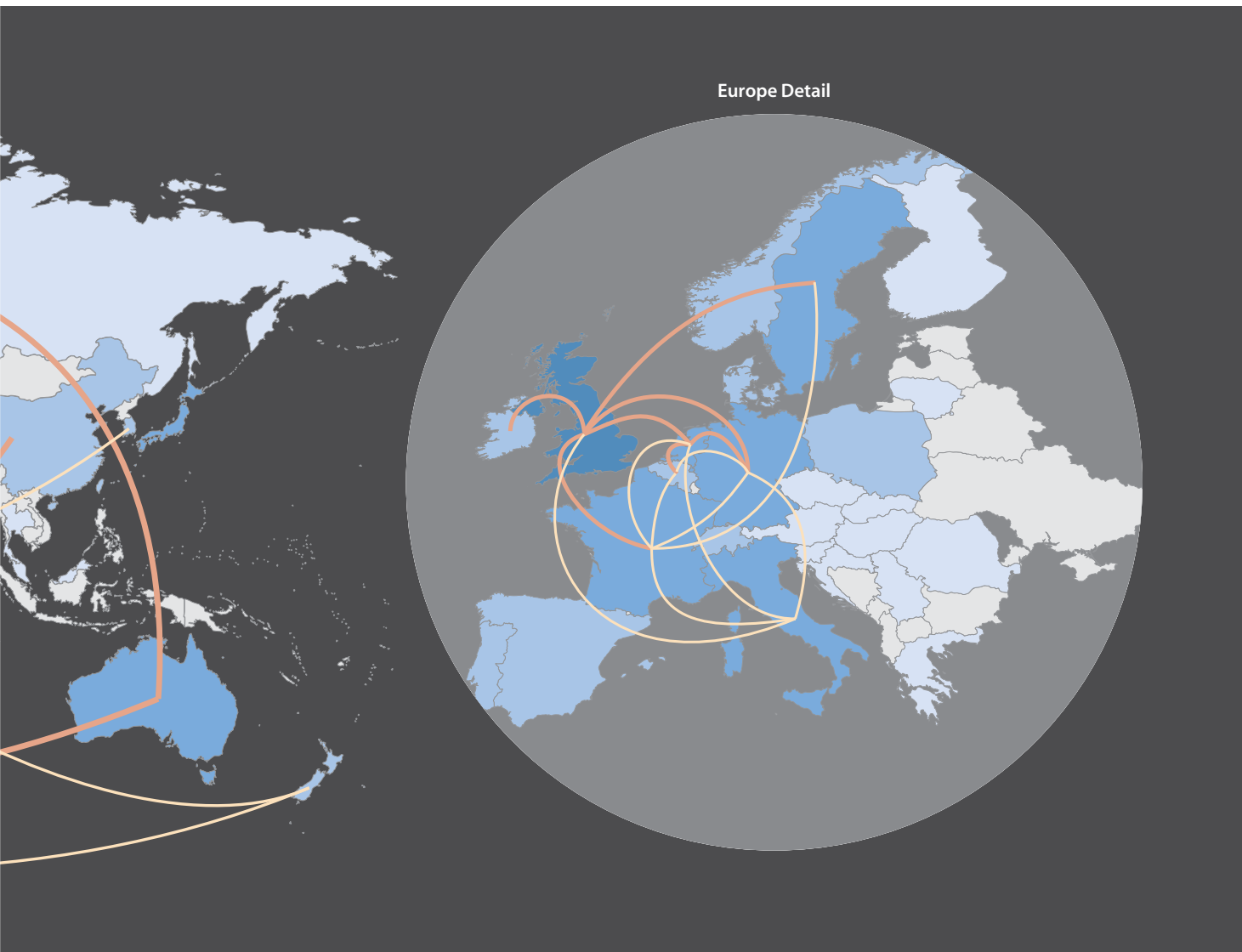


Figure 18. Extent of Global Autism Research and International Collaborations in 2010.

Varying shades of blue indicate the total publication output for a country, with lighter shades representing fewer articles and darker shades indicating more articles. Countries in gray did not publish autism research in 2010. Connecting lines between countries represent author collaboration, where thicker and darker lines indicate a greater degree of shared publications between country pairs. For figure clarity, country pairs with five or fewer collaborations are not shown. Also for clarity, intra-Europe collaborations are not shown on the world map but can be seen in the “Europe Detail” inset.

largest number of autism publications (1,040). The map shows that US-international collaborations were extensive in 2010, with the most prominent collaborations occurring between the US and Canada as well as the US and the United Kingdom (31 to 40 shared publications each). In general, the

highest levels of collaboration occurred between North America and Western Europe. Other countries with six or more international collaborations include Australia, New Zealand, Israel, Turkey, China, and South Korea. The complete list of country co-authorship pairs can be found in Appendix VI.



Rank in 2010	Author Country	Number of ASD Publications in 2000	Number of ASD Publications in 2010	Fold Growth From 2000 to 2010	Average Annual Increase in Number of Publications Since 2000
1	United States	265	1040	3.9	77.5
2	United Kingdom	94	287	3.1	19.3
3	Canada	24	137	5.7	11.3
4	Netherlands	13	97	7.5	8.4
5	Italy	22	86	3.9	6.4
6	Australia	11	85	7.7	7.4
7	France	22	78	3.5	5.6
8	Germany	9	73	8.1	6.4
9	Japan	14	69	4.9	5.5
10	Sweden	9	59	6.6	5.0
11	Israel	7	35	5.0	2.8
12	Turkey	2	34	17.0	3.2
13	China	1	31	31.0	3.0
14	Belgium	6	29	4.8	2.3
14	Spain	6	29	4.8	2.3
16	Ireland	6	25	4.2	1.9
17	Poland	0	21	N/A	2.1
18	Taiwan, Province of China	1	20	20.0	1.9
19	Norway	3	19	6.3	1.6
19	Denmark	4	19	4.8	1.5
19	Brazil	0	19	N/A	1.9
22	India	0	17	N/A	1.7
23	Switzerland	2	16	8.0	1.4
24	Korea, Republic of	1	14	14.0	1.3
24	New Zealand	2	14	7.0	1.2

Table 2. Top 25 Countries Publishing Autism Research in 2010.

This table lists the top 25 countries publishing autism research in 2010 as well as publication counts by country in 2000 and 2010. The number of ASD publications produced in 2000 and 2010 is provided for comparison of publication activity in the last decade. In order to capture growth in publication rates by country, the two columns to the right contain the fold growth in publication number between 2000 and 2010 and the average annual increase in the number of publications produced per country since 2000. In cases where a single publication contained authors from multiple countries, the publication is counted for each country.

Table 2 provides the publication counts for the top 25 most prolific countries publishing autism research in 2010. While the US leads in the number of ASD-related publications, the effort in 2010 was clearly global, with publications from authors in more than 50 different countries. To illustrate how research publication activity for each of the top 25 countries has changed in recent years, Table 2 also provides the publication counts for each country in the year 2000, as well as the fold growth in annual publication rate and the average annual increase in the number of publications since 2000. Over the last decade, the US, UK, and Canada have maintained the top three spots with respect to numbers of publications produced each year, but many developing countries have demonstrated stronger growth in publication activity. Starting from very low numbers in 2000, countries in Asia have shown some of the strongest fold growth in publication

count since 2000, including China, Taiwan, India, and South Korea. Turkey has also increased substantially its publication activity, as have Brazil and Poland, which were not linked to any ASD research articles in 2000. The complete list of author countries publishing 2010 autism publications is provided in Appendix VII.

Figure 19 and **Figure 20** further illustrate changes in autism publication activity across countries. **Figure 19** shows the total number of ASD publications for the last 30 years by country. Publications are counted on a “whole-count basis,” where each collaborating country is credited one count; therefore, multiple counting can occur if more than one country contributes to a publication. The top five countries are graphed individually and the remaining countries are grouped together and graphed as a single line, called “All Other

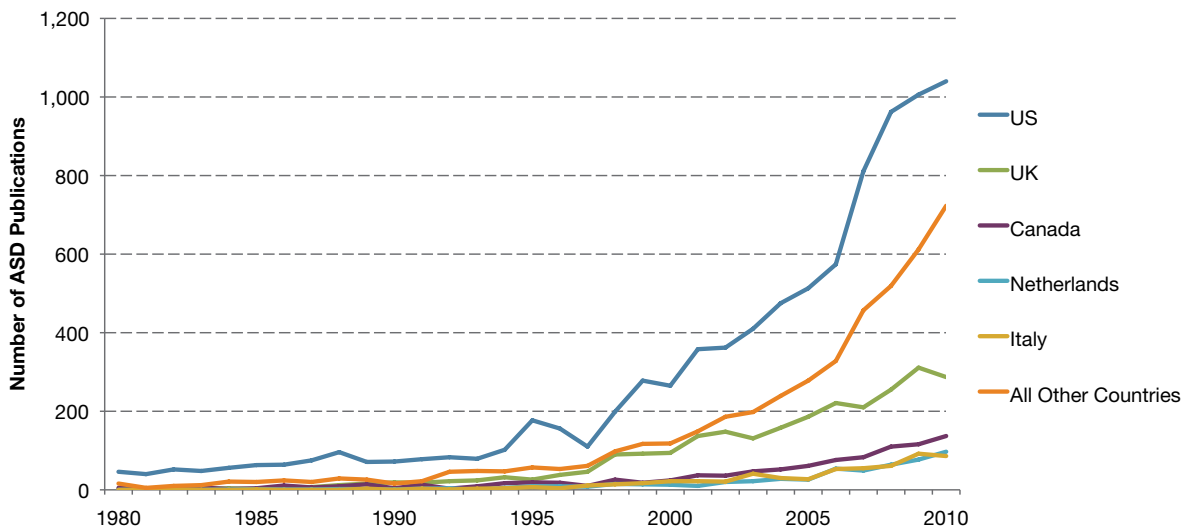


Figure 19. Global Growth in Autism Publications by Country, 1980 to 2010.

The total publication counts by country since 1980 are shown above, with the US producing the most publications (blue line). The next highest producer is the combined category that includes all countries that are not among the top five (orange line). Researchers in these countries have sharply increased their publications output since 2000. Publications are counted on a “whole-count basis,” where each collaborating country is credited one count; therefore, multiple counting can occur if more than one country contributes to a publication. For example, if there are three authors listed on a publication, two from the US and one from UK, the publication would be counted twice, once for the US and once for the UK.

Countries.” While the US and UK have consistently demonstrated the highest levels of single country outputs, there has been a recent pronounced increase in publications produced by researchers outside of the top five countries.

A distinct trend towards globalization of ASD research is demonstrated further in **Figure 20**, which plots each country’s share of the annual world autism publication output from 1980 to 2010. To determine a country’s share of total annual autism publications, publications are counted on a “whole-count basis,” where each collaborating country is credited one count. This method shows the full contribution of each country without penalizing for international collaboration. Each country’s count is divided by the total number of publications in that year to determine the country’s annual share, and can therefore add up to more than 100%.

A more complete description of methodology for calculating world share and a discussion of alternative methods that may be useful in future analyses is provided in Appendix VIII. Results of the analysis show that the collective share of the top five countries has been decreasing since 1980, while the share of the remaining countries (collectively called “All Other Countries”) has been increasing.

The countries with the highest fold growth since 2000 (provided in **Table 2**) are some of the primary contributors to the increasing share seen among All Other Countries – particularly China, Taiwan, South Korea, India, Poland, and Brazil. These data suggest a broadening of international autism research, and this trend is not unique to autism. The National Science Foundation’s *Science and Engineering Indicators 2012* published growth curves of global research outputs, demonstrating that many countries with developing

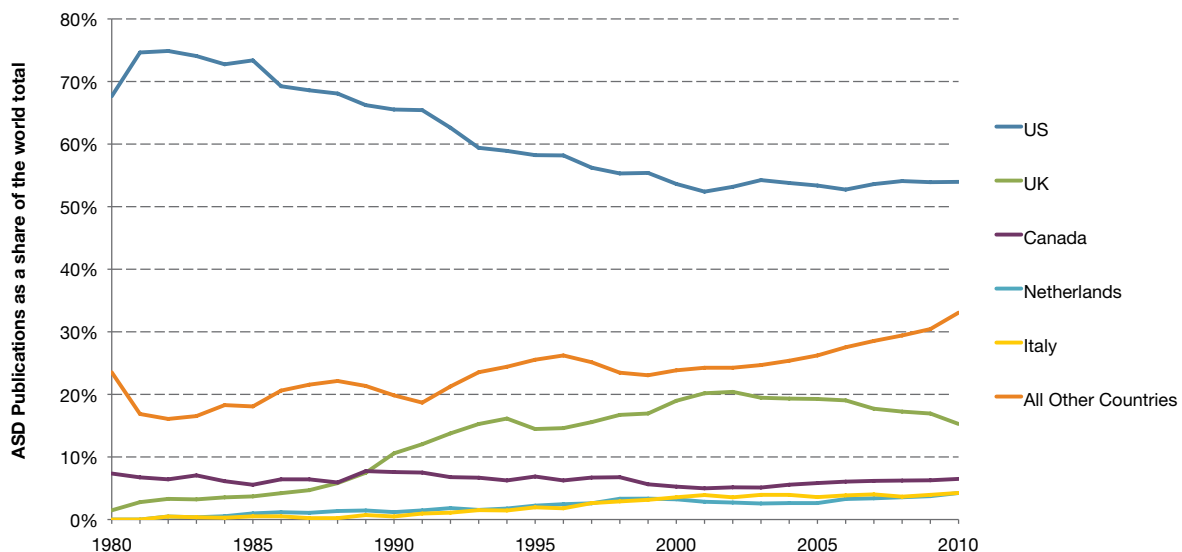


Figure 20. Author Countries for ASD-Related Publications as a Share of the World Total, 1980 to 2010.

While the world share of autism publications is increasing in countries like Italy (yellow line) and the Netherlands (teal line), the US share has decreased since 1980. Increases are also observed among countries outside the top five most prolific (collectively represented by the orange line). Publications are counted on a “whole-count basis,” where each collaborating country is credited one count; therefore, multiple counting can occur if more than one country contributes to a publication and percentages can be greater than 100.

economies are greatly increasing their research activity, particularly in Asia and South America.²⁹ Likewise, the world share of US publications across much broader science and engineering disciplines has continued to decrease in the last 15 years, and in 2010 the US accounted for approximately 28% of all science and engineering articles. In the related Journal Subject Categories utilized in this study as a closely related comparison group, the US share of publications has also been on a steady decline since 1980 and now accounts for approximately 39% of the world share, substantially lower than the 53% share observed among the focused subset of 2010 autism publications. Given broader research trends towards increased globalization of scientific output, increasing global awareness of and focus on autism as an important health issue, and potential opportunities to develop commercializable products and technologies to help people with ASD, it is likely

that a number of countries with traditionally smaller research capacities will continue to increase their autism research activities and world share of autism publications in coming years.

Are international collaborations increasing and do they result in higher impact research?

As shown previously in **Figure 18**, a number of investigators from different countries are producing collaborative publications. To examine whether international collaboration in autism research is increasing, author network analyses were conducted to visualize the number of countries participating in international collaborations. **Figure 21** shows collaboration network maps for five specific years (1990, 1995, 2000, 2005, and 2010). All countries that have published autism research since 1990 are nodes

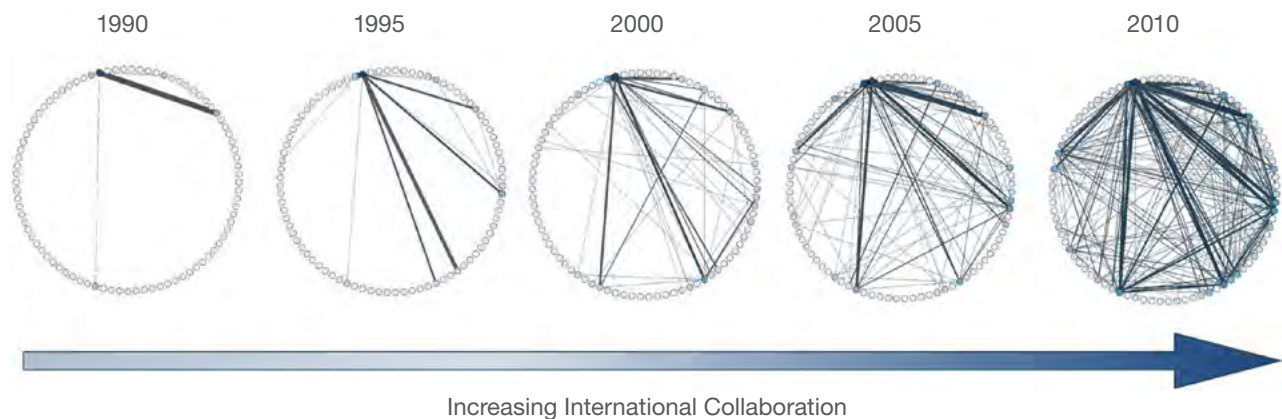


Figure 21. International Autism Publication Collaboration Networks in 1990, 1995, 2000, 2005, and 2010.

All countries publishing autism research in any year from 1990 to 2010 are represented by the smaller network of circles, or nodes, forming the boundary of the larger circles. Each line between two country nodes indicates a publication with authors from both countries within that time period. The collaboration networks clearly show a dramatic increase in international collaboration between 1990 and 2010.

on the edge of the circular network. A line, or link, between these nodes indicates a publication with authors from both countries. These network maps illustrate that not only are author collaborations growing, but more and more countries are involved in international autism collaborations.

Similarly, **Figure 22** (top left) shows the total number of ASD publications from 1980 to 2010 produced by authors in only one country (blue line) and authors in multiple countries (orange line). Both groups have increased substantially since the mid- to late 1990s. **Figure 22** (bottom right) shows the proportion of autism publications authored by researchers in

more than one country (blue line), demonstrating a clear increase from near zero in 1980 to over 20% in 2010. It appears that one out of every five autism research articles currently published is the product of international research collaboration. For comparison, the proportion of publications resulting from international collaborations in the grouping of broader Journal Subject Categories, mentioned in Chapter One and described in Appendix III, is also shown (orange line). While the trends are very similar, the autism field generally has been engaging in less international research collaboration than broader scientific fields. One interpretation is that ASD research still lags a bit behind broader scientific

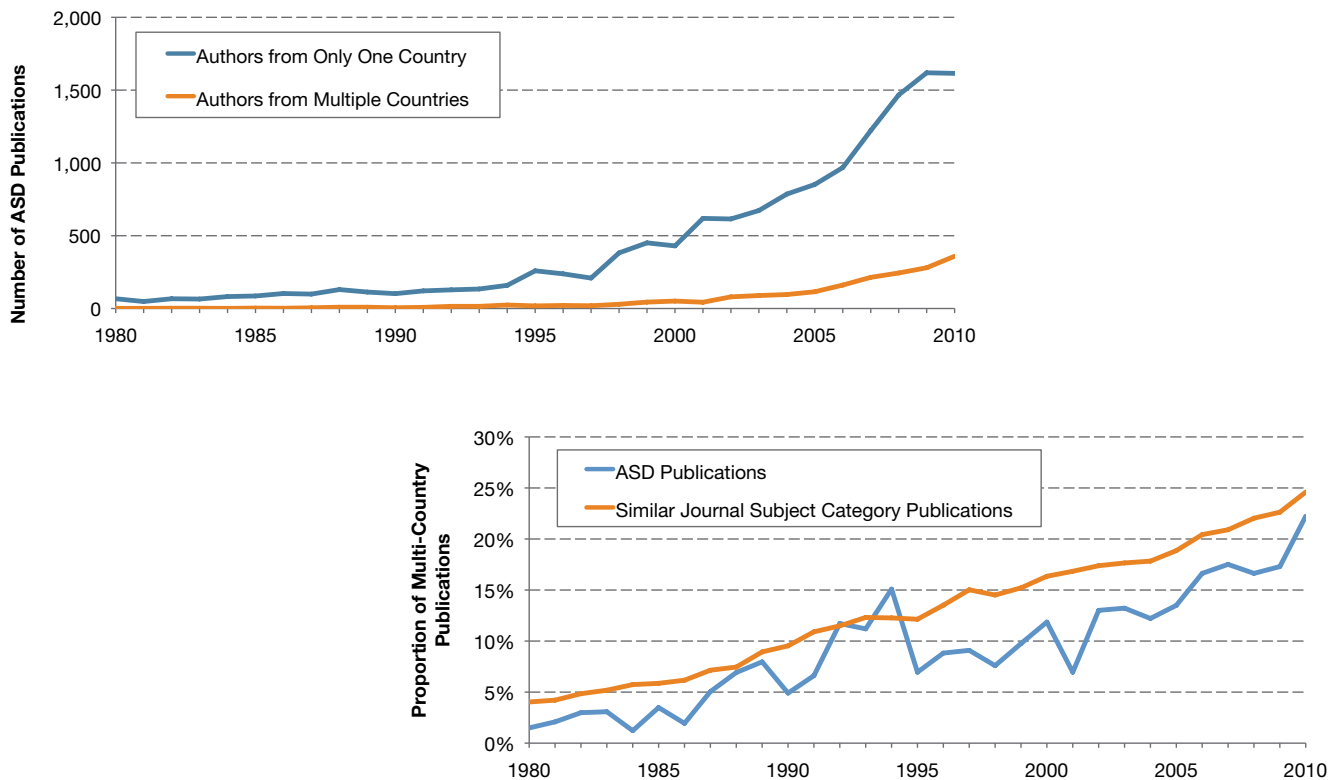


Figure 22. Extent of International Collaboration in Autism Research, 1980 to 2010.

The number (top left) and proportion (bottom right) of autism research papers with authors from multiple countries is shown from 1980 to 2010. The volume graph to the left shows that the number of publications from a single country (blue line) and publications stemming from multi-country collaborations (orange line) have increased appreciably since the mid- to late-1990s. The graph to the right plots the proportion of autism publications with authors from multiple countries (blue line) compared with the corresponding proportion in the related comparison group defined by the similar Journal Subject Category publications (orange line). Both groups demonstrate a distinct increase in international collaboration, though ASD publications generally demonstrated a lower proportion of multi-country publications than broader research fields.

fields in its extent of globalization and international collaboration, possibly due to the relatively earlier phase of development of the autism research field.

To determine whether the involvement of investigators from multiple countries results in higher impact publications, the average 2-year times cited for internationally collaborative versus single country publications were determined. **Figure 23** shows that autism publications with authors from more than one country are consistently cited more often than those from a single country. While these data are preliminary and further, more rigorous analyses would be needed to demonstrate whether this trend is upheld when controlled for variables such as author and institution number, the trend shown here suggests that international, collaborative publications may be reaching more researchers and therefore impacting a larger portion of the research community.

Combined, all of these collaboration indicators, including the number of countries participating in research across national borders, the share of

publications with international authors, and the suggested high impact of publications resulting from international collaboration may have key implications. First, as the autism research field expands, researchers across numerous countries are increasingly collaborating and publishing together. Second, since these collaborations appear to be producing publications that are cited more often, it suggests that the results of these collaborations may be reaching more researchers across the global community and may have higher influence within the field. The observation that international collaborations represent a smaller proportion of ASD publications than what is found in the collection of comparable Journal Subject Categories covering a broader array of science may be another sign that the autism field is still in a relatively early stage of development. Observations from this section and the previous section showing that more countries are becoming more involved in autism research over time suggests that opportunities for international collaboration will continue to increase for some time to come.

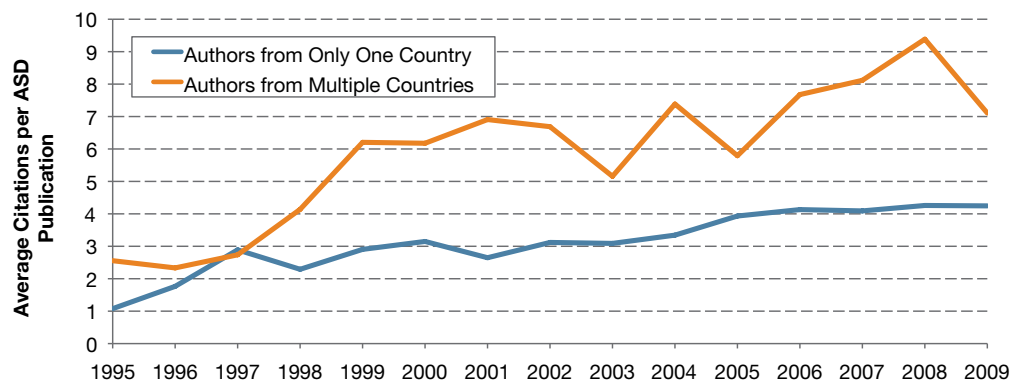


Figure 23. Impact of Collaborative International Autism Publications, 1995 to 2009.

The average 2-year citations for publications with authors from a single country (blue line) compared to those from multiple countries (orange line) show that publications with authors from multiple countries receive more citations, indicating that publications authored by international collaborations may be having greater impact over time. Self-citations are not included in the 2-year citation count.

Which research institutions are publishing the most research?

More than 1,800 institutions worldwide published autism research in 2010. **Table 3** displays the 25 research institutions that published the greatest number of autism research articles in 2010. Seventeen of the top 25 institutions are in the US, but autism research is also concentrated in institutions in the UK, Netherlands, Canada, and Sweden. The vast majority of top-publishing institutions are universities, but there is one non-university institution in the top 25 – the US government’s National Institute of Mental Health, an institute of the NIH. Also noteworthy is that seven of the top-publishing US universities are hosts of NIH-funded Autism Centers of Excellence, including the University of North Carolina, University of California Los Angeles, University of Washington, Yale University, University of California Davis, University of California San Diego, and the University of Pittsburgh.^{xi}

^{xi} More information on NIH’s Autism Centers of Excellence can be found in the Biennial Report of the NIH Director, 2008-2009: <http://report.nih.gov/biennialreport/ViewSection.aspx?sid=28&cid=4>.

Do institutional collaborations result in higher impact research?

Similar to examining the citation impact of collaboration between countries, citation counts were also used to assess the influence of publications resulting from institutional collaboration identified by using author address data. Results showed that as the number of institutions per publication increases, there is a corresponding increase in the average number of times a publication is cited (**Figure 24**). These results parallel the findings concerning international collaborations and lend additional support to the hypothesis that, within the ASD field, when institutions share knowledge and resources, publication outcomes are strengthened. Other studies have also demonstrated a growing trend toward multi-institutional collaboration in virtually all fields of science, engineering, and social science, and further show that collaboration tends to result in more highly-cited publications.^{30,31}

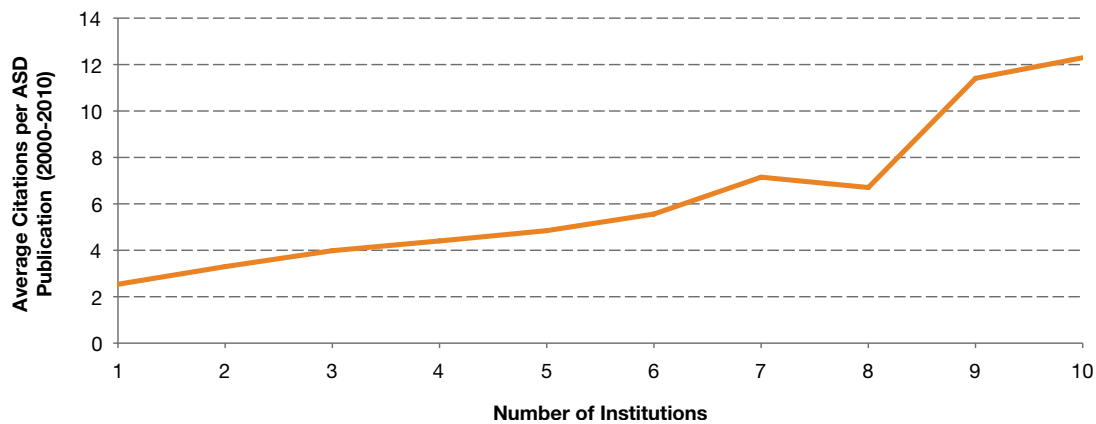


Figure 24. Impact of Collaborative Publications with Authors from Multiple Institutions, 2000 to 2010.

The graph above illustrates the correlation of the 2-year average times cited with the number of institutions collaborating on the same research publication for all publications from 2000 to 2010. There is an increase in the average number of citations as the number of institutions involved in the research increases.

	Institution	Country	Total Publications
1	Harvard University	United States	46
2	University of North Carolina	United States	44
3	King's College London	United Kingdom	42
4	University of California Los Angeles	United States	39
5	Radboud University Nijmegen	Netherlands	36
6	University of Washington	United States	34
6	Yale University	United States	34
6	University of California Davis	United States	34
9	University of Wisconsin	United States	33
10	McGill University	Canada	30
11	University College London	United Kingdom	29
11	University of Pennsylvania	United States	29
13	National Institute of Mental Health	United States	29
14	Louisiana State University	United States	27
15	University of Gothenburg	Sweden	26
16	Vanderbilt University	United States	25
17	University of California San Diego	United States	24
17	Ohio State University	United States	24
17	Boston University	United States	24
20	University of Toronto	Canada	23
20	Columbia University	United States	23
22	Karolinska Institute	Sweden	22
22	University of Pittsburgh	United States	22
22	University of Utah	United States	22
25	University of Montreal	Canada	21

Table 3. Top 25 Institutions Publishing Autism Research Globally in 2010.

This table, listing the institutions that published the most autism research in 2010, shows that institutions worldwide are making significant contributions to the autism field. Each of the top 25 most prolific universities and institutions are included, along with their country and the number of 2010 publications

Which US states are publishing autism research?

As noted previously, more than 50% of 2010 autism publications were authored by at least one researcher at a US institution. US publications were examined in more detail by mapping the total number of publications at the State level and also measuring the extent of institutional and international collaboration in the subset of papers that included US authors.

Figure 25 illustrates the pattern of publication density across the US, which may reflect several key factors including population, centers of research

activity, and levels of government funding for research. Due to variations in these factors, research outputs vary widely from state to state. California, Massachusetts, and New York are the most prolific autism research publishing states; they are also the top three recipients of Federal health-related research dollars.^{xiii}

Are US researchers engaging in more institutional and international collaboration?

To determine the extent to which US researchers are collaborating with investigators at other US institutions and abroad, ASD research publications with authors located in the US were grouped

^{xiii} For more state by state details on US health-related Federal research funding provided by the NIH, the Centers for Disease Control and Prevention (CDC), and the Agency for Healthcare Research and Quality (AHRQ), see http://www.researchamerica.org/state_funding.

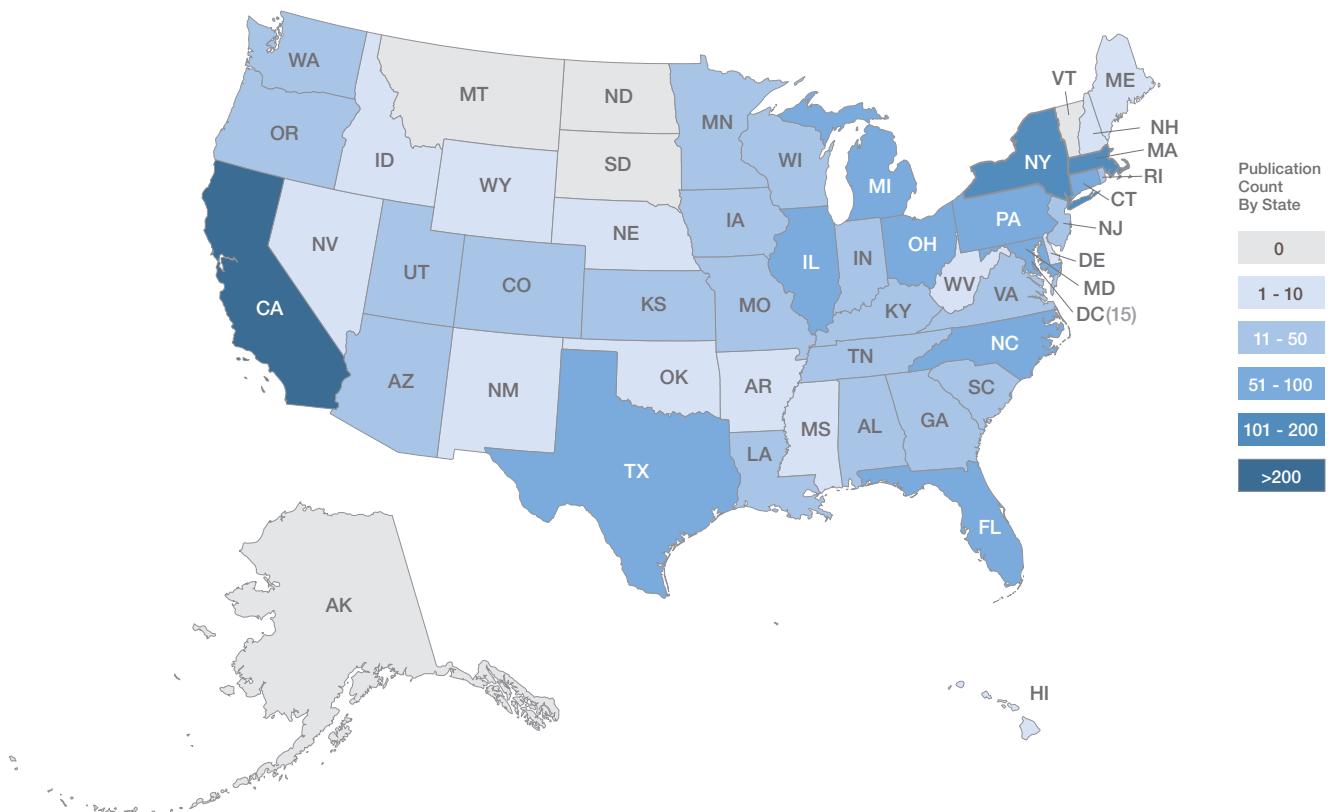


Figure 25. State by State Number of US Autism Publications in 2010.

Increasingly darker shades of blue indicate increasing volumes of State-level autism publications. California, Massachusetts, and New York are the states publishing the largest volume of autism research articles. States in gray were not linked to any autism-relevant publications in 2010.

into three categories. The first category contains publications from a single US institution. The other two categories contain multi-institution publications, either between multiple institutions within the US (but not non-US institutions) or between US and non-US institutions, indicating a US-International collaboration. **Figure 26** shows the number of publications produced in these three respective categories (top left) and the proportion of total for publications from 1980 to 2010 (bottom right). From 1998 onwards, the publication rate of articles in all three categories increased. Before the mid-2000s, it was more common for publications to result from US researchers working within the boundaries of a single institution (shown in blue). In

the last few years, however, that trend has reversed – publications from single US Institutions only accounted for 40% of 2010 autism research articles, and it is now more common for US investigators to publish with collaborators at other universities in the US and abroad. Both categories of multi-institution publications have increased, especially since 2000, and combined they accounted for 60% of all ASD publications with US authors in 2010. Publications from multiple institutions in the US (shown in green) have doubled, increasing from approximately 20% in 1995 to 40% in 2010. In that same time period, collaborative US-International publications also doubled, up from around 10% to 20%. Given the strong recent trends in

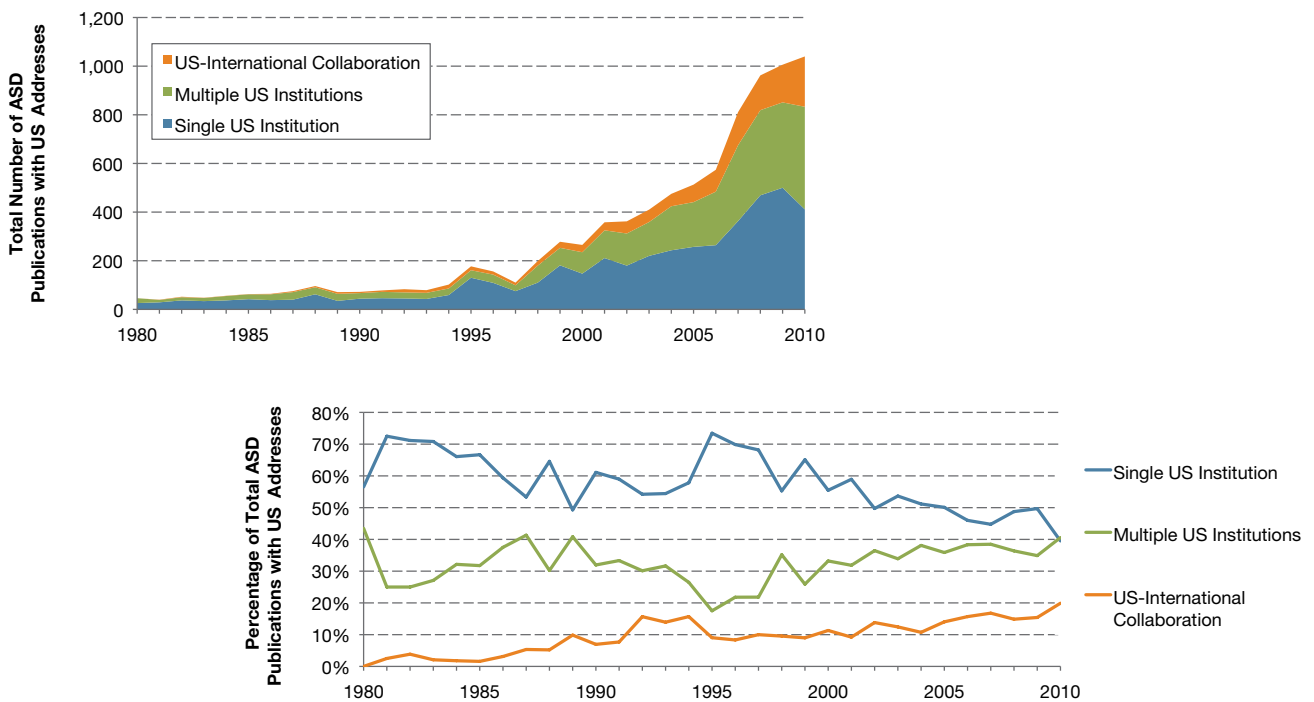


Figure 26. Extent of Institutional and International Collaboration in US Autism Research, 1980 to 2010.

The number (top left) and proportion (bottom right) of US-authored publications from 1980 to 2010 that were affiliated with a single US institution (blue), multiple US institutions (green), or a US plus a non-US institution (orange). For the stacked area graph (left), the total area that is shown in color represents the total number of publications per year from 1980 to 2010. This has been divided into three portions, representing the respective publication counts within each of the three categories. There has been an increase in the number of publications in all three categories since the late 1990s, culminating in 2010 with 40% of the publications coming from single US institutions, 40% from multiple US institutions and 20% from collaborations between US and international institutions. The line graph to the right shows that while single institution publications, at one time, made up the largest proportion of US publications, the number of multiple institution publications is now larger, accounting for a combined 60% (i.e., the combined total of “Multiple US Institutions” and “US-International Collaboration”) – driven both by an increase in the proportion of publications from multiple institutions in the US and the proportion of publications resulting from US-International collaborations.

multi-institution publications in the US autism research field, collaborative projects should continue to play an influential role in the future.

In conclusion, similar trends toward increasing collaboration in autism research are evident in the United States and abroad. Increasing institutional and international collaboration is likely supporting the rise of knowledge creation and exchange among institutions and across national boundaries. Investigators, institutions and funders should continue to encourage and support collaboration, as sharing intellectual and research resources has the potential to accelerate research progress.

Main findings from analysis of global autism publications and collaborations

1. In 2010, autism research was published by authors in over 50 countries and more than 1,800 research institutions worldwide.
2. Since 1980, US investigators consistently have been the largest producers of autism publications, but the US's share of autism research has declined over time, stabilizing to around half of the world share in 2010.
3. In the last decade, the share of publications from countries outside of the top 5 publishers has increased. Leading this trend are many developing countries in Asia, especially China, Taiwan, South Korea, and India, as well as Poland and Brazil.
4. Collaborative publications, either between multiple countries or multiple institutions, are increasing and are also more highly cited than publications with authors from only one country or only one institution, suggesting that international and multi-institution research efforts may have a higher impact in the autism field.
5. Multi-institutional publications, consisting of authors at different institutions within the US as well as US institutions collaborating with non-US institutions, are now more common than those produced from authors located at a single US institution.

CONCLUSION

The goal of this broad, preliminary analysis of ASD research publication data was to examine the development and current state of autism science to inform the strategic planning efforts of the Interagency Autism Coordinating Committee (IACC) and to help various stakeholders gain insight into the possible impacts and implications of ASD research activities and investments. Publications serve as a primary output of research efforts, and an in-depth understanding of autism publication trends can help research funders, policymakers, researchers and other community stakeholders design strategies to maximize progress and cultivate breakthrough research. The data presented in this report can be used to identify potential areas of need as well as opportunities to leverage strengths across funding sources and research communities.

Collectively, the findings presented in this study suggest that autism research is a young but rapidly evolving and growing field. The recent rise in autism research publications has been remarkable, particularly since 1999, when the growth in autism publication rates began to far outpace comparable research literature. Using several parameters related to autism publications, research activity as measured by publication output was found to be expanding across all areas of the *IACC Strategic Plan*, with strong growth in publication rates in the last decade. The largest proportion of publications were related to the *Biology* Critical Question area (38%

of 2010 autism publications), which encompasses a broad range of basic research focused on clarifying the underlying biological mechanisms that contribute to ASD. Publications that address *Treatments and Interventions* and *Risk Factors* had the second and third highest output in 2010 (19% and 17%, respectively). Overall, the Critical Question categories related to more basic research, particularly *Biology* and *Risk Factors*, demonstrate more publication activity than the translational categories of *Diagnosis* and *Treatments and Interventions*, which supports the hypothesis that autism research is still in a relatively early stage of development, though evolving rapidly. In the future, it will be important to track whether autism research activities shift from a basic science and discovery phase to one that is more translational, with a stronger focus on the development of practical applications in the clinic and in the community, indicating increasing maturity of the field.

Spotlights on the *Risk Factors* and *Treatments and Interventions* Critical Question areas, which are of particularly high interest in the autism stakeholder community, revealed important research trends in each group. Within the set of *Risk Factors* research publications, though *Genetic Risk Factor* research accounted for a majority of 2010 publications (56%), the number of publications on *Environmental Risk Factor* research accounted for 39% of 2010 *Risk Factor* publications and has been increasing at a

rate similar to that for *Genetic Risk Factors* for the past decade. *Epigenetic* publications accounted for a relatively small share (5%) of autism research publications in 2010, but this emerging area of research has been growing appreciably since 2006. *Risk Factor* publication trends indicate that *Environmental* research activity is strong and that major advances in genetics and more recently in the understanding of epigenetics appear to be taken up quickly by the autism risk factor research community. The spotlight on *Treatments and Interventions* also highlighted emerging areas, showing a recent increase in publications related to *Occupational, Physical, and Sensory-Based Therapies* as well as *Complementary, Dietary, and Alternative Interventions* in the last few years. *Behavioral* interventions accounted for the largest proportion of publications in this Critical Question area (26%), followed by *Medical/Pharmacologic* treatments (18%), which have grown substantially since 1995. Since 2000, the strongest growth was observed for publications in the *Technology-Based Interventions and Supports* subcategory, and this trend is likely to continue as broader scientific and technological innovations continue to advance.

Commensurate with rising ASD research publication counts, autism research articles are arguably demonstrating greater research impact, with citation rates increasing between 1980 and 2009. Moreover, the average number of citations that autism publications receive was found to be higher than that of publications in comparable research fields, and the proportion of highly cited autism publications has been generally increasing since 1995. Recognition of autism publications in the scientific community has increased, particularly in the last decade, and mirrors the heightened awareness of autism in the public sphere, lending further support to the idea that the autism research field is growing and increasing in maturity.

Just as the NIH funding for autism has increased substantially in the last 10 to 15 years, results of this analysis indicate that this may be true for global autism funders, as well. While it was beyond the scope of this report to estimate global funding trends for autism, this report examined the publication activity of global funders acknowledged for supporting autism research articles published in 2010. Although autism funding acknowledgment analysis was limited by a low proportion of articles containing funder acknowledgments, the most-acknowledged funders of autism publications still likely represent major contributors to global ASD funding.

More than 700 different funding organizations were acknowledged in 870 autism articles published in 2010, consisting of an international mix of governmental agencies and private organizations. Approximately one-third of publications with funding acknowledgments cited some combination of US government, US private, and international funding support, indicating that the research community is leveraging investments from many funding sources to support research activities. The pattern of research topics supported by different funders – namely US government, US private, and non-US funders – is generally the same, with the strongest emphasis on *Biology, Treatments and Interventions*, and *Risk Factor* research for all three funder types.

As mentioned, a major limitation to the comprehensive analysis of research publication output from funders was imposed by the low proportion of funding acknowledgments found in 2010 autism publications (36%). With only approximately one-third of research articles citing funding, estimation of the outputs resulting from funder investments and productivity of global research institutions was significantly constrained.

It is probable that many funders of autism research were not acknowledged for their support, making it impossible to ascertain the full scope of the outputs resulting from their investments. In the current era of tightening research budgets in the US and a number of other world economies, it is critical for funding organizations to demonstrate that research investments are resulting in positive outputs and outcomes to justify continued and enhanced research support. Thus, it is critically important for funders, policymakers, research institutions, and scientific publishers to encourage more accurate acknowledgment of funding within the various disciplines of ASD research to ensure sustained support and continued growth of the field.

This analysis also illustrates that autism research is an increasingly global endeavor. US investigators have been and continue to be the most prolific publishers of autism research; however, it is encouraging to see that other countries have substantially augmented their research efforts in recent years. With trends toward many non-US countries such as China, South Korea, India, Japan, Finland, and Germany as well as many other developing countries increasing the percentage of their gross domestic product devoted to research and development efforts, we expect that the autism research outputs of non-US countries will continue to increase.³²

Finally, a defining trend revealed in this analysis is that research efforts are increasingly collaborative, crossing both institutional and national boundaries. In 2010, more than 20% of autism publications listed authors from multiple countries, which was double the proportion observed in 2000 and substantially higher than that seen in 1980, when it was near zero. The trend toward increasing collaboration is not limited to shared efforts between small groups of top-publishing countries. The network of international collaboration is increasingly

being shaped by a growing number of country partners. It also appears that multi-institutional and multinational autism research publications are particularly influential, as they tend to be more frequently cited by their research peers.

In conclusion, the trends revealed by this analysis suggest that the young and rapidly growing field of autism research is benefiting from scientific advances in related emerging fields, increasing in impact, and becoming more collaborative and global. The US and the global autism research community should continue to leverage scientific opportunities and public and private investments in autism science. Critical research discoveries are still needed to find solutions to the most pressing medical and social challenges faced by people with autism, their families, and their communities. The in-depth description of the global autism research publications landscape provided in this report can aid the collective efforts of the IACC and broader autism stakeholders to enhance research efforts that can address the urgent need for more effective diagnostics, treatments and interventions, and services to meet the needs of individuals and families affected by autism across the lifespan.

REFERENCES

- ¹ US Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008. *Morbidity and Mortality Weekly Report*. 2012 March 30;61(SS03);1-19.
- ² Interagency Autism Coordinating Committee. *2011 IACC Strategic Plan for Autism Spectrum Disorder Research*. January 2011. Retrieved from the Department of Health and Human Services Interagency Autism Coordinating Committee website at <http://iacc.hhs.gov/strategic-plan/2011/index.shtml>.
- ^{3,8,19} Office of Autism Research Coordination, National Institute of Mental Health, on behalf of the Interagency Autism Coordinating Committee (IACC). *2010 IACC Autism Spectrum Disorder Research Portfolio Analysis Report*. July 2012. Retrieved from the Department of Health and Human Services Interagency Autism Coordinating Committee website: <http://iacc.hhs.gov/portfolio-analysis/2010/index.shtml>.
- ^{4,25,30} Jones BF, Wuchty S, Uzzi B. Multi-university research teams: shifting impact, geography, and stratification in science. *Science*. 2008 Nov 21;322(5905):1259-62.
- ^{5,26,31} Wuchty S, Jones BF, Uzzi B. The Increasing Dominance of Teams in Production of Knowledge. *Science*. 2007 May 18; 316 (5827), 1036-1039.
- ⁶ Office of Autism Research Coordination, National Institute of Mental Health, on behalf of the Interagency Autism Coordinating Committee (IACC). *2008 IACC Autism Spectrum Disorder Research Portfolio Analysis Report*. 2009. Retrieved from the Department of Health and Human Services Interagency Autism Coordinating Committee website: <http://iacc.hhs.gov/portfolio-analysis/2008/index.shtml>.
- ⁷ Office of Autism Research Coordination, National Institute of Mental Health & Acclaro Research Solutions, Inc., on behalf of the Interagency Autism Coordinating Committee (IACC). *2009 IACC Autism Spectrum Disorder Research Portfolio Analysis Report*. June 2011. Retrieved from the Department of Health and Human Services Interagency Autism Coordinating Committee website: <http://iacc.hhs.gov/portfolio-analysis/2009/index.shtml>.
- ⁹ Simons Foundation. SFARI Gene Website. Accessed on June 20, 2012; available at https://gene.sfari.org/autdb/HG_Home.do
- ¹⁰ Betancur C. Etiological heterogeneity in autism spectrum disorders: more than 100 genetic and genomic disorders and still counting. *Brain Res*. 2011 Mar 22;1380:42-77.
- ^{11,12} Geschwind DH. Genetics of autism spectrum disorders. *Trends Cogn Sci*. 2011 Sep;15(9):409-16.
- ¹³ Hertz-Picciotto I, Croen LA, Hansen R, Jones CR, van Water J, Pessah IN. The CHARGE study: an epidemiologic investigation of genetic and environmental factors contributing to autism. *Environ Health Perspect*. 2006;114:1119-1125.
- ¹⁴ LaSalle JM. A genomic point-of-view on environmental factors influencing the human brain methylome. *Epigenetics*. 2011 Jul;6(7):862-9.
- ¹⁵ Gropman AL, Batshaw ML. Epigenetics, copy number variation, and other molecular mechanisms underlying neurodevelopmental disabilities: new insights and diagnostic approaches. *J Dev Behav Pediatr*. 2010 Sep;31(7):582-91.
- ¹⁶ Lovaas, O. Ivar. Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*. 1987;55(1):3-9.
- ¹⁷ Smith T. Outcome of early intervention for children with autism. *Clinical Psychology: Science and Practice*. 1999;6:33-49.
- ¹⁸ C. Maurice, G. Green, S.C. Luce (Eds.), Behavioral intervention for young children with autism: A manual for parents and professionals, Pro-Ed, Austin, TX (1996).
- ^{20,21} Costas R and van Leeuwen TN. Approaching the 'Reward Triangle': general analysis of the presence of funding acknowledgments and 'peer interactive communication' in scientific publications. Preprint of article accepted for publication in *Journal of the American Society for Information Science and Technology*. 2012; available at <https://openaccess.leidenuniv.nl/handle/1887/18648>
- ²² Bordons M, Gómez I, Fernández MT, Zulueta MA, Méndez A. Local, domestic and international scientific collaboration in biomedical research. *Scientometrics*. 1996;37:279-295.
- ²³ Sin, S.-C. J. International coauthorship and citation impact: A bibliometric study of six LIS journals, 1980-2008. *J. Am. Soc. Inf. Sci*. 2011;62:1770-1783.
- ²⁴ Katz, J., & Hicks, D. How much is a collaboration worth? A calibrated bibliometric model. *Scientometrics*. 1997;40(3), 541-554.
- ²⁷ Lee K, Brownstein JS, Mills RG, Kohane IS. Does Collocation Inform the Impact of Collaboration? *PLoS ONE*. 2010; 5(12): e14279.
- ²⁸ Moed, H.F. Citation analysis in research evaluation. 2005. Dordrecht, Netherlands: Springer.
- ²⁹ National Science Board. 2012. *Science and Engineering Indicators 2012*. Arlington, VA: NSB: 12-01.
- ³² The World Bank. April 2012. *World Development Indicators 2012*. Data retrieved June 20, 2012, from World Development Indicators (WDI) Online database: <http://data.worldbank.org/indicator/GB.XPD.RSDV.GD.ZS>

ABBREVIATED APPENDICES

Appendix I: Methodology for Identifying ASD-Related Research Publications and Supplemental Primary Research Publication Counts

An automated keyword search was used to identify publications that contained the terms “autism,” “autistic,” “Asperger,” or “pervasive developmental disorder” in the journal title, article title, article abstract or article keywords. Publications tagged with the MEDLINE MeSH terms “Asperger syndrome,” “autistic disorder,” or “child development disorders, pervasive” were also collected and classified as ASD-related. MeSH terms are only present for articles with records in MEDLINE.

The Thomson Reuters ScienceWire™ Publication Catalog, a central database that includes publication records for both the MEDLINE section of PubMed and the Thomson Reuters Web of Science® (WoS) was used for this keyword search. For instances in which publication records were identified in both the MEDLINE and WoS databases, a thorough de-duplication algorithm was applied to merge the two records into a single publication record. In cases for which the same record was identified in both databases and resolved to a single publication, WoS data were preferentially presented above MEDLINE data, with missing data points populated using MEDLINE, as available. Several data points are only available from WoS; therefore preferential usage of WoS data presents a more consistent set of data points for analysis. These data points include:

1. Citation Counts
2. Journal Subject Categories
3. Keywords

In the rare instance that the data fields in the two databases were sufficiently different, the same publication may be present multiple times. For example, if a publication has the same title and journal, but different publication dates or authors listed in the two databases, these are reported as two separate publications. It is estimated that this may happen in approximately 1% or fewer of the publications.

MEDLINE and WoS have different indicators for document type. Whereas WoS assigns a single article type to a publication, MEDLINE may assign multiple article types. Publications were classified as primary research, secondary research or meeting abstract based on the general guidelines listed below.

1. Publication records classified as “meeting abstract” in the WoS were excluded from this analysis because there was usually insufficient text to indicate a specific category.
2. Secondary research articles included:
 - a. WoS Editorials
 - b. Articles with the classifications outlined in Table A-4 and all articles from one of 81 specified journals in the WoS that are known to publish primarily secondary research articles (Table A-5).
3. All other articles were considered primary research.

Regardless of whether analyses included the combined categories of primary and secondary research publications or were restricted to primary research only, very similar trends and distributions of publication output across the Critical Question areas were observed. The following figures include only primary research publications and are companions to Figures 8-11 in the body of the report, which demonstrate combined primary and secondary research publication output.

For example, Figure A-27 draws from the same data set as Figure 8; however, Figure A-27 plots primary research publication counts by Critical Question area, whereas Figure 8 plots the combined counts of primary and secondary research publications.

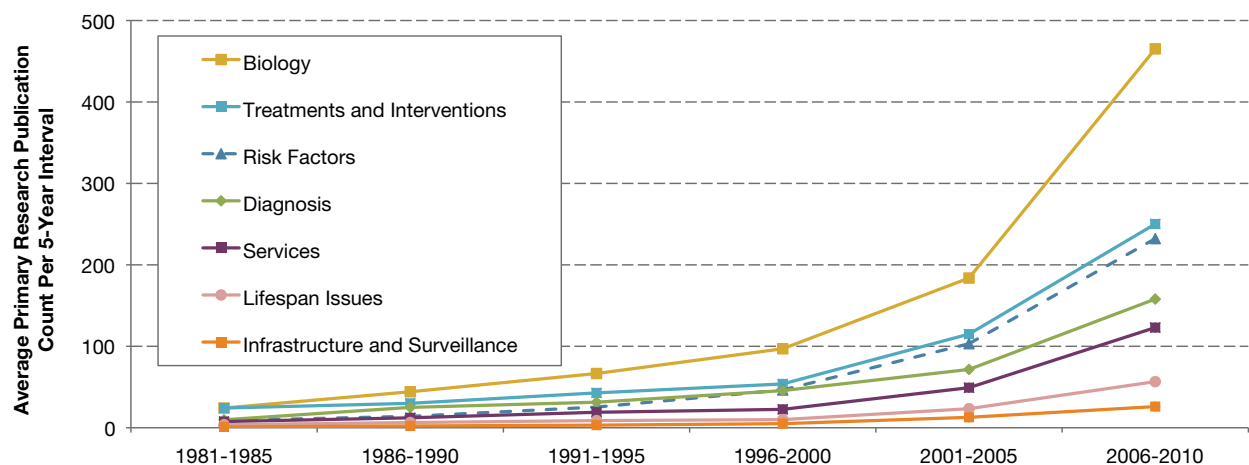


Figure A-27. Growth in ASD Primary Research Publications by Critical Question Area, 1981 to 2010.

The growth trends in primary research publication output by Critical Question areas of autism research over the past 30 years illustrate very similar patterns as Figure 8, which plots the combined output of primary and secondary research publications by Critical Question area. Each data point represents a five-year average of the number of annual autism publications.

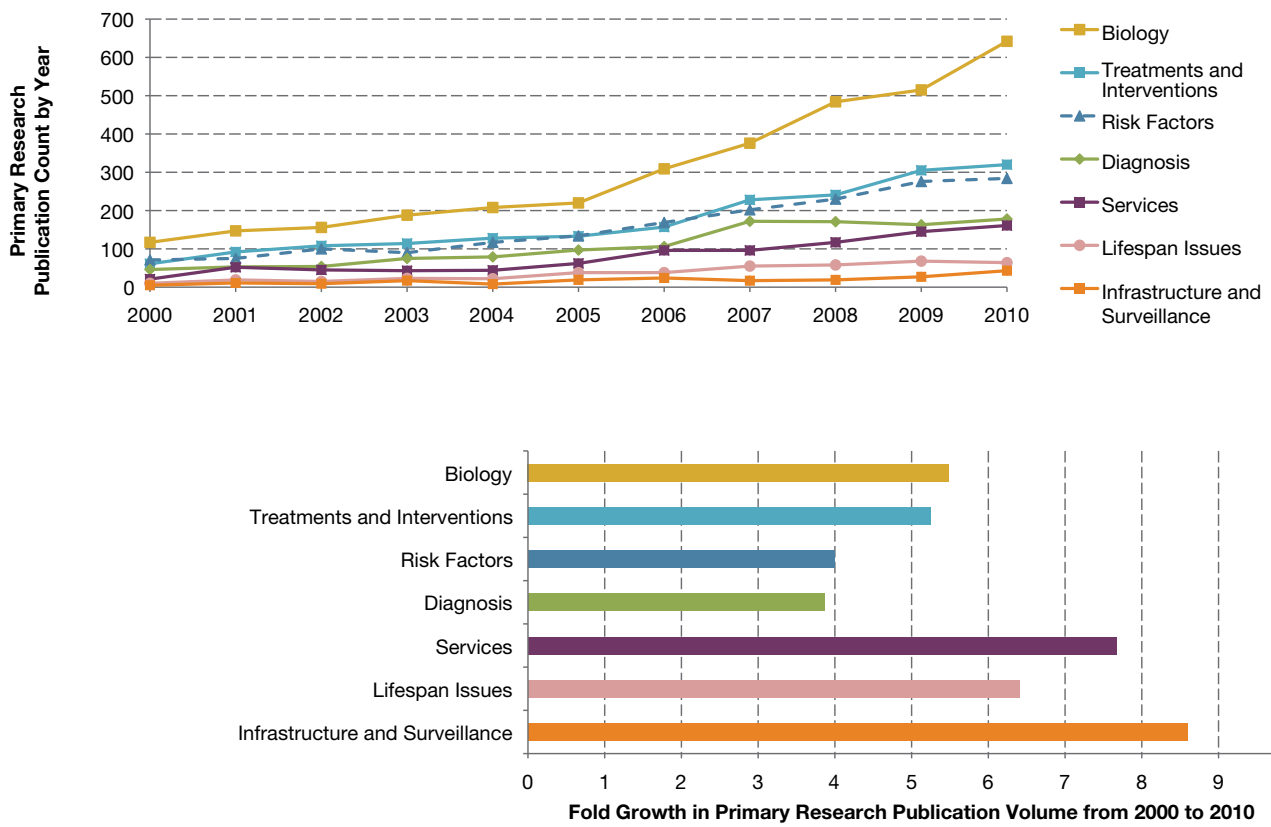


Figure A-28. Number and Fold Growth of ASD Primary Research Publications from 2000 to 2010.

This figure illustrates number (top left) and fold growth (bottom right) of primary research publications within the Critical Question areas since 2000. Recent primary research publication growth trends are very similar to growth of combined primary and secondary research trends illustrated in Figure 9. Both show that while *Biology* maintains the largest proportion of publications, other areas are growing at least as quickly, including *Infrastructure and Surveillance*, *Services*, and *Lifespan Issues*.

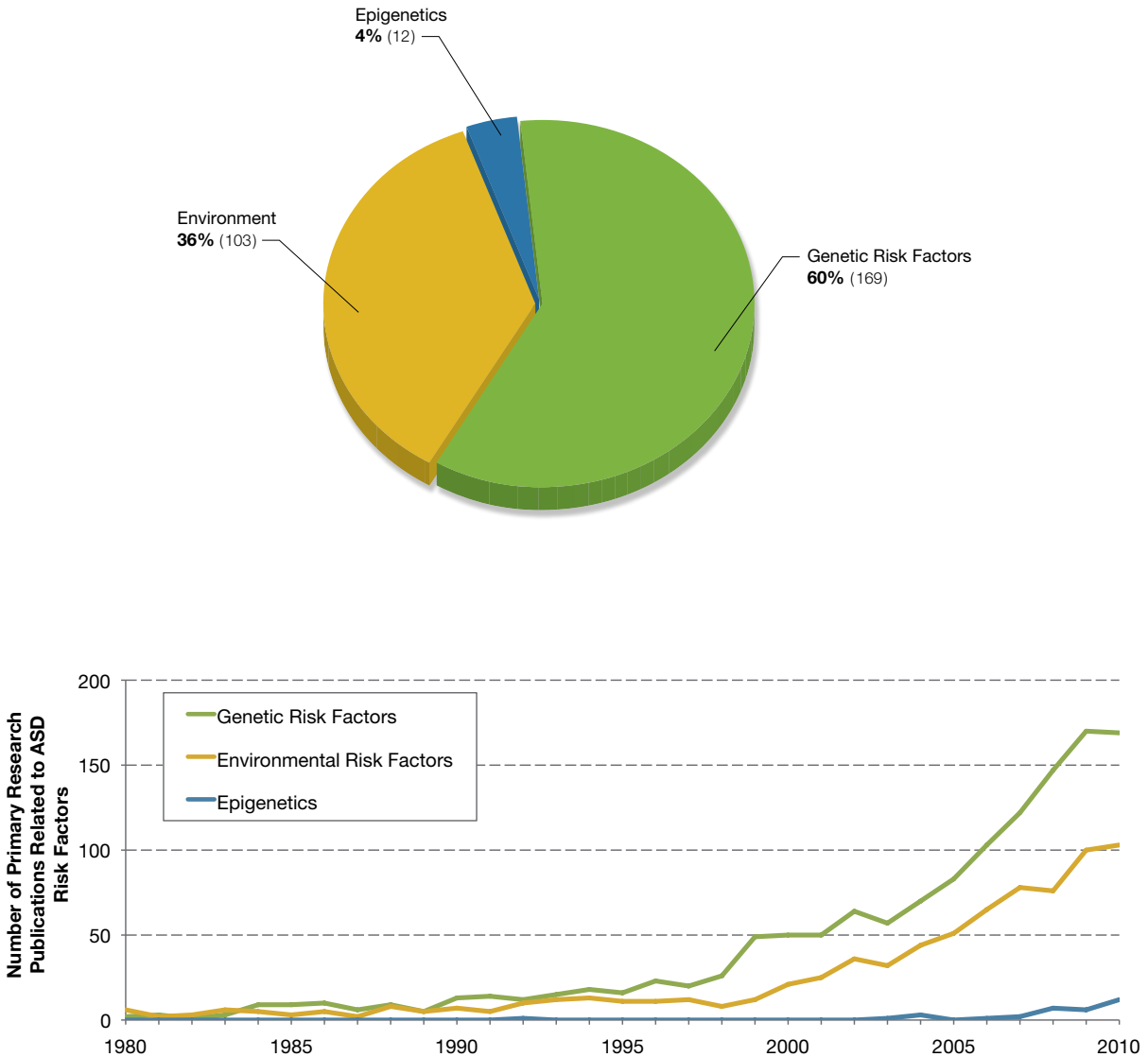


Figure A-29. Primary Research Publication Output and Trends in Subcategories of Autism Risk Factor Research.

The pie graph (top) illustrates relative proportions of primary research articles published in 2010 in three subcategories of ASD Risk Factor research and the line graph (bottom) shows the increase in number of publications in each subcategory over time from 1980 to 2010. Similar to the distribution of both primary and secondary research publications illustrated in Figure 10, *Genetic Risk Factors* research had the greatest number and proportion of publications, followed by *Environmental Risk Factors* and then *Epigenetics*.

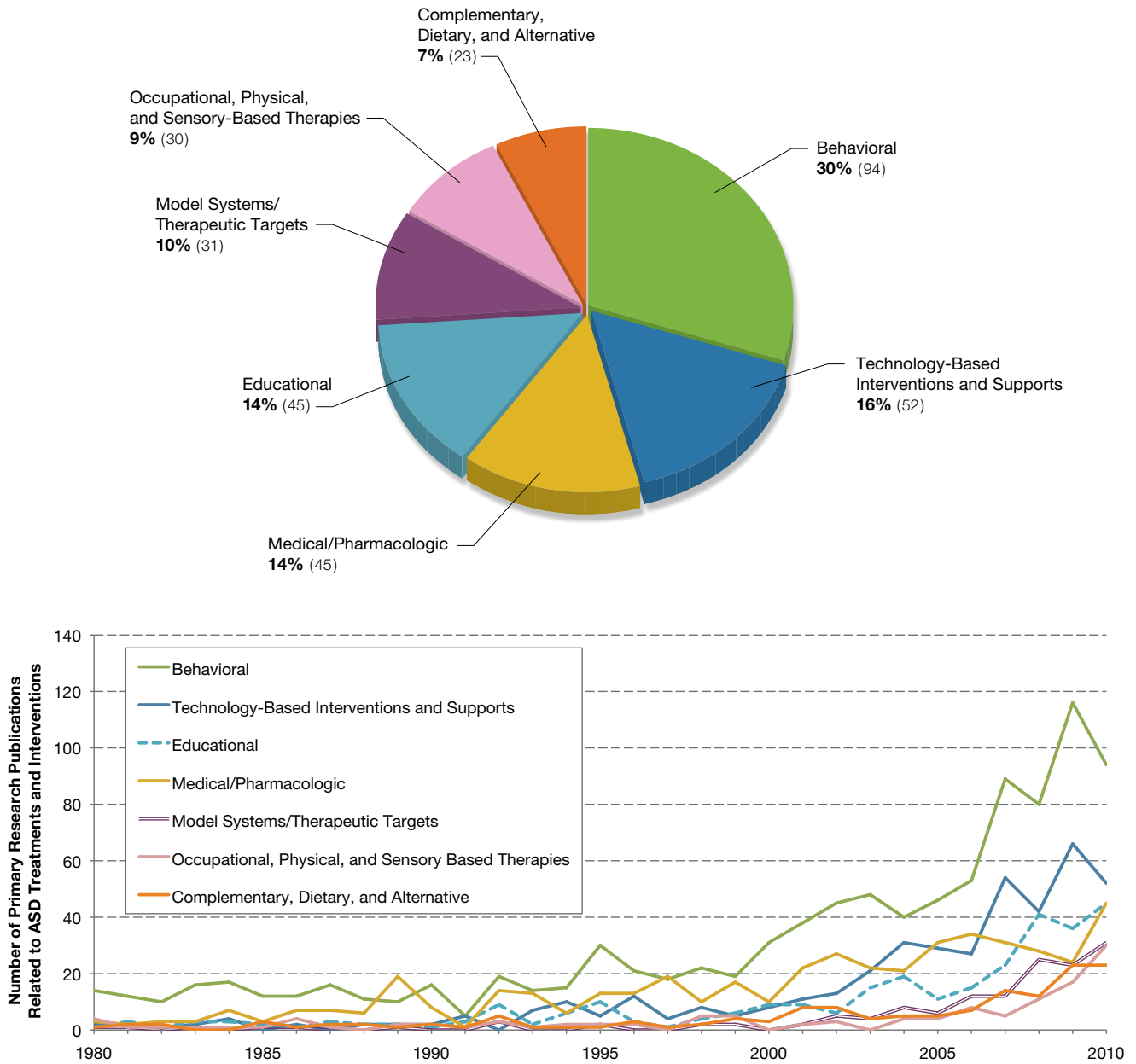


Figure A-30. Primary Research Publication Output and Trends in Subcategories of Autism *Treatments and Interventions* Research.

The pie graph (top) illustrates relative proportions of primary research articles published in 2010 on seven subcategories of ASD *Treatments and Interventions* research and the line graph (bottom) shows the change in number of publications in each subcategory over time, from 1980 to 2010. Similar to the combined distribution of primary and secondary *Treatments and Interventions* research publications illustrated in Figure 11, the most prolific areas of primary research include *Behavioral*, *Technology-Based Interventions and Supports*, *Medical/Pharmacological*, and *Educational* interventions.

Table A-4. Web of Science® and MEDLINE Article Types Classified as Secondary Articles

WoS	MEDLINE
Review	Addresses
Book Review	Bibliography
Database Review	Clinical Conference
Hardware Review	Comment
Software Review	Consensus Development Conference
Art Exhibit Review	Consensus Development Conference, NIH
Film Review	Dictionary
Music Score Review	Directory
Record Review	Duplicate Publication
Music Performance Review	Editorial
Theater Review	Government Publications
TV Review, Radio Review, Video	Guideline
Dance Performance Review	Interactive Tutorial
	Interview
	Introductory Journal Article
	Lectures
	Legal Cases
	Legislation
	Letter
	News
	Newspaper Article
	Overall
	Patient Education Handout
	Periodical Index
	Practice Guideline
	Published Erratum
	Retracted Publication
	Retraction of Publication
	Review
	Scientific Integrity Review
	Technical Report
	Congresses
	Historical Article

Table A-5. Journals in which All Publications Were Classified as Secondary Research

American Family Physician	Trends In Neurosciences
American Psychologist	University Of Toronto Quarterly
Behavioral Healthcare	Genetic Engineering & Biotechnology News
Biology & Philosophy	Forbes
BMJ (Clinical Research Ed.)	Canadian Geographer-Geographe Canadien
British Journal Of Hospital Medicine	Revue Médicale Suisse
Cornell Law Review	School Nurse News
Cultural Studies	Review Of Law And Social Change. New York University
Current Opinion in Psychiatry	The American Psychologist
Current Opinion in Neurology	Behavioral And Brain Sciences
Current Treatment Options In Neurology	11th International Conference On Control, Automation, Robotics And Vision (ICARCV 2010)
Dentistry Today	17th International Conference On Biomagnetism Advances In Biomagnetism - Biomag2010
Educational Leadership	2010 ACM Conference On Computer Supported Cooperative Work
Exceptionality	2010 Annual International Conference Of The IEEE Engineering In Medicine And Biology Society (EMBC)
Expert Review Of Clinical Immunology	2010 IEEE International Conference On Acoustics, Speech, And Signal Processing
F1000 Biology Reports	2010 IEEE International Conference On Image Processing
Forum Der Psychoanalyse	2010 IEEE International Conference On Image Processing
Healthcare Quarterly (Toronto, Ont.)	2010 IEEE International Conference On Robotics And Automation (ICRA)
Human Studies	2010 International Joint Conference On Neural Networks IJCNN 2010
La Revue Du Praticien	Advances In Web-Based Learning-ICWL 2010
LÄKartidningen	ASSETS 2010: Proceedings Of The 12th International ACM SIGACCESS Conference On Computers And Accessibility
LaKartidningen	CHI2010: Proceedings Of The 28th Annual CHI Conference On Human Factors In Computing Systems, Vols 1-4
Medical Hypotheses	Computer Safety, Reliability, And Security
Mens Sana Monographs	Computers Helping People With Special Needs, Proceedings, Pt 2
Mosaic-A Journal For The Interdisciplinary Study Of Literature	Conference On Environmental Pollution And Public Health, Vol 1-2
Neuroforum	Entertainment Computing - ICEC 2010
Phenomenology And The Cognitive Sciences	Evolution Of Language, Proceedings
Philosophical Explorations	Future Generation Information Technology

continued

Table A-5. Journals in which All Publications Were Classified as Secondary Research

Philosophical Quarterly	IEEE Virtual Reality 2010, Proceedings
PSN-Psychiatrie Sciences Humaines Neurosciences	International Conference On Learner Diversity 2010
Psyche-Zeitschrift Fur Psychoanalyse Und Ihre Anwendungen	Medical Image Computing And Computer-Assisted Intervention - MICCAI 2010, Pt I
Psychological Bulletin	Photonic Therapeutics And Diagnostics VI
Rhetoric Society Quarterly	Proceedings Of 2010 International Conference On Behavioral, Cognitive And Psychological Sciences
Scientific American	Selected Topics In Applied Computer Science
State Legislatures	Ubicomp 2010: Proceedings Of The 2010 ACM Conference On Ubiquitous Computing
Studia Phaenomenologica	WCPCG 2010
The Harvard Mental Health Letter / From Harvard Medical School	XIV European Conference On Developmental Psychology (ECDP)
The Journal Of Medical Humanities	ICIEA 2010: Proceedings Of The 5th IEEE Conference On Industrial Electronics And Applications, Vol 4
The Pennsylvania Nurse	Security-Enriched Urban Computing And Smart Grid
The Practitioner	Biomedical Sciences Instrumentation

Appendix II: Automated Categorization of ASD Publications (1980-2009)

Manual assignment of the more than 20,000 ASD related publications between the years of 1980 to 2009 to the seven *IACC Strategic Plan* Critical Question areas would have required significant effort and resources. As a proxy for this manual review, publications were assigned using the semi-automated k-nearest neighbor (*k*-NN) algorithm.

As a first step in this approach, subject matter experts reviewed all of the 2010 ASD publications and manually assigned them to different research areas and subcategories based on the titles and abstracts of the specific publication. ASD publications from 1980 to 2009 (“prior publications”) were then categorized based on their similarity to the previously classified 2010 publications. Prior publications were compared to 2010 publications and assigned a similarity score based on a modified

Okapi BM25 algorithm. These publications were assigned to the category of the mode of the 25 publications from 2010 with the highest similarity scores. This approach to categorize publications was chosen because of the performance as well as accuracy and ease of use. Initial tests for automated categorization using other algorithms including Naïve Bayesian, supervised Latent Dirichlet, Boosting and Tree algorithms, all showed accuracy of much less than 70%.

While some publications naturally span multiple research categories, each publication is assigned to only one category for ease of tracking and trend analyses. Using this approach errs on the side of potentially underestimating the volume of research in some categories.

Appendix III: Web of Science® Journal Subject Categories

Journal Subject Category: Journals indexed in Web of Science are manually assigned to a Journal Subject Category based on an assessment of the applicable research field. These subject categories are used in the Journal Citation Reports®. Under this scheme, journals may be classified under more than one of the over 270 subject categories, and a given journal may be assigned to multiple categories to reflect the diverse nature of literature it publishes. Every article within a given journal inherits the subject category of the journal itself. To establish an appropriate and informative comparison group, the current ASD publications analysis used Journal Subject Categories to identify publications that are similar in discipline to those within the ASD publication portfolio.

The distribution of ASD publications by Journal Subject Category is presented in **Table A-6** below. These Journal Subject Categories were used to establish a baseline for comparing the growth of ASD publications since 1980. For this comparison, the total publications within these Journal Subject Categories in each year was multiplied by the total ASD publications in 1980, then divided by the total publications within the Journal Subject Categories in 1980. The resulting values indicate the expected number of ASD publications based on the rate of growth within the comparable Journal Subject Categories.

Table A-6. Comparison Group: Journal Subject Categories Comprising 75% of ASD Publications Since 1980

Deluxe Journal Subject Category	Number of ASD Related Publications	% of Total	Cumulative %
Psychology, Developmental	6,066	15%	15%
Psychiatry	5,470	13%	28%
Neurosciences	3,782	9%	38%
Clinical Neurology	2,866	7%	45%
Rehabilitation	2,627	6%	51%
Pediatrics	2,251	6%	57%
Genetics & Heredity	1,963	5%	62%
Education, Special	1,948	5%	66%
Psychology, Clinical	1,242	3%	69%
Psychology	1,037	3%	72%
Behavioral Sciences	901	2%	74%
Psychology, Experimental	748	2%	76%

Appendix IV: Web of Science® Citation Data

Citation counts were used in Chapter Two to measure the impact and maturity of the autism research field as well as in Chapter Four to address the impact of collaborations. When appropriate, we used the average field-normalized citation count to ensure that the data were compared adequately between autism and other research fields.

Citations: The citation count is the number of times that a citation has been recorded for a given publication since it was published. Not all citations are recorded since not all publications are indexed. However, the material indexed by Thomson Reuters is estimated to attract about 95% of global citations. The two-year citation counts used in some of the current analyses include only those citations made

within 730 days of publication. This limitation allows for comparison across publications that have had different lengths of time to accumulate citations.

Average normalized citation impact/count:

Citation rates vary across research fields and from one time period to another. Consequently, analyses must take both field and year into account. In addition, the type of publication will influence the citation count. For this reason, only citation counts of papers of the same document type are used in calculations of citation impact. The standard normalization factor is the world average citations per paper for the year and journal category in which the paper was published. This normalization is also referred to as 'rebasings' the citation count.

Appendix V: Full Funder List for 2010 ASD Publications

This appendix is available on the IACC website: www.iacc.hhs.gov.

Appendix VI: Country Co-Authorship Pairs in 2010 ASD Publications

This appendix is available on the IACC website: www.iacc.hhs.gov.

Appendix VII: 2010 ASD Publication Counts by Country

This appendix is available on the IACC website: www.iacc.hhs.gov.

Appendix VIII: Methodology for Calculating World Share of Autism Research Publications

Publications are counted on a “whole-count basis,” where each collaborating country on a given publication was credited one count. For example, if there are three authors listed on a publication, two from the US and one from UK, the publication would be counted twice, once for the US and once for the UK. To determine the country’s annual share, each country’s count is divided by the total number of publications in that year. This method shows the full contribution of each country without penalizing for international collaboration.

An alternative method is the fractional approach, where each participating country receives a fraction of the count. Using this approach would be appropriate for other types of analyses in which the purpose is to highlight countries that publish singly versus those that publish mainly as a result of international collaborations. A fractional approach would show a lower volume for countries that publish only collaboratively and would not accurately reflect the total number of publications from each country as intended in the current analysis. In 2010, approximately 20% of ASD research articles result from international collaborations, and the whole count methodology works well for the ASD field at its current stage, but in the future, if the field becomes increasingly collaborative across international borders, the fractional count method may be more useful.

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