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ORIGINAL PAPER

Trends in US Autism Research Funding

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Abstract This study shows that the number of autism research grants funded in the US from 1997 to 2006 significantly increased 15% per year. Although the majority of projects were concentrated in basic science (65%) compared to clinical (15%) and translational research (20%), there is a significant decrease in the proportion of basic research grants per year and a significant increase in the proportion of translational projects per year. The number of translational projects funded by the National Alliance for Autism Research and Cure Autism Now increased significantly, whereas the number of clinical projects significantly increased for the National Institutes of Health. In conclusion, this study demonstrates the shifting landscape of autism research from basic science to clinical and translational research.

Keywords Autism spectrum disorder · Funding · Neurogenetics · Treatment · Diagnosis

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Introduction

During the last two decades autism has moved from relative obscurity to the center of media attention and public awareness. No other child psychiatric disorder has seen such an increase in fund raising activities and lobbying for federal dollars. Public expectations of quick breakthroughs in autism research, especially among parents of children with autism, are very high (Aarons and Gittens 1999; Bazell 2005). Very little is known about the causes of autism and no specific brain pathology has been described. Abnormalities found in a relatively small number of postmortem brains are subtle and not restricted to one particular brain area (Bauman and Kemper 2005). Currently there are no drugs that affect the core symptoms of autism (Rutter 2006) and the mainstay of therapy is behavioral. Not surprisingly, many parents put their trust in one of the increasing number of alternative therapies and are becoming more and more critical of mainstream medical treatments (Levy et al. 2003; Hanson et al. 2007). In this climate, setting funding priorities is a daunting task and questions about the types of studies that have benefited most from the recent funding boost, and their impact, must be asked. It is also important to delineate the changes in autism research and the degree successes of basic research have been translated into promising clinical trials and treatment for individuals with autism.

Funding for autism research within the National Institutes of Health (NIH) has increased fivefold since 1997,

from $22 to $108 million in 2006 (Coalition to Protect Research 2005; NIH 2007a; Vitiello and Wagner 2007). The majority of this research is funded through the National Institute of Mental Health (NIMH), the leading federal agency for biomedical research on autism. Other NIH institutes with significant autism research portfolios are the National Institutes of Child Health and Human Development (NICHD), Neurological Disorders and Stroke (NINDS), and Deafness and Other Communication Disorders (NIDCD). The priorities of autism research in the US are a testament to a recent statement at the 2007 International Meeting for Autism Research, where the director of the NIMH, Tom Insel stated, "I spend more time on autism than on all mental health problems combined" (Insel 2007).

The mandate of NIH is to consider not only science in the laboratory, but also, the burden of specific diseases, the public health needs of society, existing scientific opportunities, and the quality, experience and sustainability of research protocols (Coalition to Protect Research 2005). The steep rise in research funding for autism is often justified by the increase in prevalence, which in 2007 was reported by the Center for Disease Control and Prevention (CDC) to be 1 in 150 children (CDC 2007a). Some argue that the rise in funding for autism research has hindered funding in other disease areas such as Down's syndrome, cystic fibrosis or childhood leukemia, which have all seen marked decreases in NIH funding dollars since 2003 (Wadman 2007). However, a comparison of autism with other diseases and conditions based on prevalence and NIH funding levels in fiscal year 2006 shows that funding priorities of the NIH are not necessarily correlated with prevalence (Table 1).

In addition, the input of disease advocacy groups often influences research directions and priorities (NIH 2007b). Given recent constraints on the NIH budget (Mervis 2007), allocation of funds to a specific disorder will affect the availability of resources to diseases with weak patient or advocate organizations. Parent advocacy groups have been instrumental in lobbying the federal government to fund research into the "cause, treatment, and ultimately a cure for autism" (Autism Speaks 2007a). Autism also became the first specific disease to have its own Senate hearing (Insel 2007). The Combating Autism Act passed the upper chamber unanimously in August of 2006 and was signed by President Bush in December of 2006. Under the new law, NIH funding for autism research will increase to $210 million by 2011 (Stokstad 2007) and an additional $21 million will be provided to the CDC. In addition, the Defense Appropriations Bill set aside $7.5 million for autism research in 2007 fiscal year. These Congressional Special Interest Medical Research Programs, funded through the Department of Defense, are limited to a small number of diseases including prostate and ovarian cancers, neurofibromatosis, military health, and other specified areas.

Advocacy groups are not only influencing research priorities by lobbying the government and increasing awareness, they are also raising money to fund their own research (Silverman and Brosco 2007). The National Alliance for Autism Research (NAAR) was established by parents of a child with autism in 1994 and was the first nonprofit in the US dedicated to funding and accelerating biomedical research in the autism spectrum disorders (Autism Speaks 2007b). Cure Autism Now (CAN) was also founded by parents of a child with autism in 1995 to focus on innovation to the causes, prevention, treatment and a cure for autism and related disorders (CAN 2007). These two major fundraising organizations for autism research merged recently into one large entity "Autism Speaks" (Autism Speaks 2006a, 2007c). This merger was based on the organizations' mutual commitment to accelerate and fund

Table 1 Prevalence and funding levels for various diseases, conditions, and research areas, based on actual grants, contracts, and research conducted at the National Institutes of Health (NIH)

Disease/condition	Estimated prevalence[a]	NIH funding levels[b]
Fragile X	1 in 4,000 males (0.025%)	$20
	1 in 6,000–8,000 females (0.017–0.013%)	
Down's syndrome	1 in 800 live births (0.12%)	$13
Anorexia	0.5–3.7% females	$14
Autism	1 in 150 children (0.7%)	$108
	(<8 years of age)	
Schizophrenia	1.1% of population	$363
Attention deficit disorder	6.5% (3–17 years of age)	$115
Depression	9.5% of population	$334

[a] Prevalence data from NIH and the Center for Disease Control and Prevention (CDC) (2000–2007). Fragile X (CDC 2006), Down's syndrome (NICHD 2006), Anorexia (NIMH 2001a), Autism (NIMH 2007), Schizophrenia (NIMH 2001b), Attention deficit disorder (CDC 2007b) and Depression (NIMH 2000)

[b] US dollars in millions for fiscal year 2006 (NIH 2007a)

biomedical research, to increase awareness of the nation's fastest-growing developmental disorder, and to advocate for the needs of affected individuals and families. In June 2006 and again in December 2006, Autism Speaks' funded over $16.9 million on projects that cover a broad range of autism sciences, including cognitive/motor processing, diagnosis, epidemiology, genetics, language and communication, neurobiology, neuroimaging, immunology, neuropathology and treatment (Autism Speaks 2006b, c).

The current funding landscape raises a number of pressing questions: what types of studies are being conducted within the landscape of autism research and what are the changes over time? Are the priorities for autism research different for advocacy-based private organizations compared to governmental funding organizations? What influence have parent advocacy groups had on the landscape of autism research? Our goal here is to find the answers to these questions.

Methods

We evaluated trends in research funding for Autism Spectrum Disorders (ASD) in the United States from 1997, when the first increase in autism funding was implemented, until 2006, the latest year for which complete data on funding for this study was available.

Data Retrieval

We retrospectively analyzed newly funded projects and programs sponsored by the US National Institutes of Health (NIH) and two US parent advocacy groups, NAAR and CAN (1997–2006). Together these agencies represent the vast majority of funding for autism in the United States. For the NIH, we retrieved data from the Computer Retrieval Information on Scientific Projects (CRISP) database using the keywords "autism" or "autistic" in the search terms and "new" award type in the CRISP query form (CRISP 2007). The CRISP database included the title, abstract, specific aims, funding agency, the name and academic rank of principal investigator, and year(s) of funding of NIH-funded protocols during the specified time period. It did not provide the US dollar amount or the specific research protocols. We retrieved the abstract, titles, the academic rank of principal investigator and year(s) of funding of NAAR and CAN-funded projects from their publicly accessible websites (Autism Speaks 2007d). Research projects with only a title available and no abstract were accepted if the theme and category could be deduced by both coders from the title (e.g., "MRI studies of cognition and sensorimotor integration in children and adults with autism") and discarded if the title was generic or obtuse. A total of 140 were coded with the title only.

For the year 2006, Autism Speaks replaced NAAR as the funding source. All non-autism specific programs and projects and data on funds restricted to training, fellowships, or conferences were excluded. Projects that focused exclusively on Asperger's Syndrome were excluded from the analysis and accounted for less then 1% of the data ($N = 3$).

Data Analysis

We manually converted the data of all eligible, newly funded programs and projects into a Filemaker Pro Database. The data were coded and quantified for the following themes: brain and behavior, which included sub-themes of neurology, neuropsychology, and behavioral manifestations; genetics, which included sub-themes of gene expression, gene discovery and pharmacogenetics; environmental causes; treatment, which included sub-themes of psychoeducational treatment, psychopharmacological treatment, and complimentary and alternative medical treatment; epidemiology; diagnosis, which included the development or assessment of tools, behavioral markers, and biological markers, and family and services. These categories were derived from a previous study of autism funding in the US and UK (Charman and Clare 2004). All multisided projects were counted for each grant at each site. Two raters (JS and JI or the research intern) coded all the data based on themes (e.g., brain and behavior) and sub themes (e.g., neurology, neuropsychology, and behavioral manifestations). In a pre-test, inter-rater reliability between pairs of raters on a random sub-sample of 50 research projects was excellent (97%; Kappa = 0.915). The data were then separated into one of three different categories of basic research only (i.e., projects coded for either brain and behavior, genetics, or environmental causes), clinical research only (i.e., projects coded for either treatment, diagnosis, epidemiology, and family and services), and translational research (i.e., projects coded with at least one code from basic research and one code from clinical research). For example, brain and behavior research would include research studies such as the electrophysiological and functional magnetic resonance imaging of social cognition in autism; clinical research would include studies such as early intensive behavioral intervention and pharmacological treatments; and translational research would include studies such as the genotype and phenotype response to treatments of autism.

All estimates and tests of changes over time for the total numbers of projects of various types were based on Poisson regression, a standard statistical model for count data. The model with year as the only predictor was fit to the entire

data set to determine overall trends and to subgroups, and to determine trends by type of sponsor and by type of project. As a log-linear model, the Poisson model reports a per-year percent change in the number of projects of a particular type. All estimates and tests of changes over time for the proportion of projects of various types were based on logistic regression, a standard statistical model for proportions. Because of the increase in total numbers, it is possible for a particular type to increase in number over time, but decrease in proportion relative to other types. Logistic regression models included year as the single predictor and were fit to all projects and separately, by type of sponsor. The logistic regression model reports a per-year change in the odds of a project being of a specific type. Odds ratios are for 1 year to the next. All analyses were carried out in Stata (StataCorp 2007). All tests were two-tailed at the 5% significance level.

Results

We coded and analyzed a total of 741 projects and programs; 304 from the NIH; 259 from NAAR; and 178 from CAN. The majority of projects were awarded to academic institutions. The predominant funding institute within the NIH was NIMH followed by NICHD. Overall, there is a significant increase in the number of funded research grants that focus on autism spectrum disorders in the US from 1997 to 2006 (15% increase per year, $z = 10.26$, $p < 0.001$). This upward trend in the number of projects is evident in all three categories of research: basic, clinical, and translational research. However, translational research leads the upward trend with a 22% increase per year ($z = 6.36$, $p < 0.001$), followed by clinical research (18%) ($z = 4.71$, $p < 0.001$) and basic research (12%) ($z = 6.91$, $p < 0.001$) (Fig. 1; Table 2).

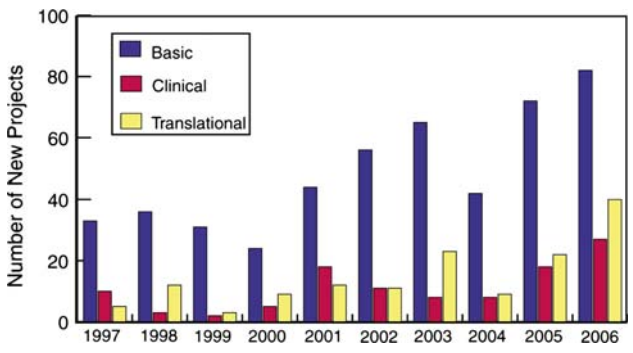

Fig. 1 Number of new US autism research grants with a theme of basic science (i.e., brain and behavior, genetics and environmental causes), clinical research (i.e., treatment, diagnosis, epidemiology, and family and services), and translational research (i.e., at least one basic code and one clinical code)

Table 2 Number of new projects for each category coded for public (NIH) and private (NAAR and CAN) sponsors

Project type	Public		Private	
	1997–2001	2002–2006	1997–2001	2002–2006
Basic	73	87	95	230
Clinical	21	39	17	33
Translational	29	55	12	50
Total	123	181	124	313

Note: Basic research consists of projects coded for brain/behavior, genetics, and/or environmental causes; clinical research consists of projects coded for treatment, diagnosis, epidemiology and/or family and services; translational research consists of projects coded with both basic and clinical research codes

NIH National Institutes of Health; *NAAR* National Alliance for Autism Research; *CAN* Cure Autism Now

The majority of projects are concentrated in basic science research (65%) compared to clinical research (15%) and translational research (20%). As we previously reported (Singh et al. 2007), "brain and behavior" is the most common research theme in all years. Second to brain and behavior is research on the genetics of autism. Compared to these two major areas of research, the others are much less represented. Only a small number of studies focus on epidemiology or family function and services available to individuals with autism (Table 3).

Figure 2 shows the proportion of grants each year of being basic, clinical or translational among all the sponsors. Despite the upward trend suggested by Fig. 1, Fig. 2 shows that there is a significant downward trend in basic only grants as a percentage of total grants (O.R. = 0.93, $z = -2.47$, $p = 0.013$) (Fig. 2). This is due partly to the significant decrease in the proportion of brain and behavior research (O.R. = 0.94, $z = -2.05$, $p = 0.041$). Conversely, there is a significant upward trend in translational research grants as a percentage of total grants (O.R. = 1.08, $z = 2.18$,

Table 3 Number of new projects for each theme coded for public (NIH) and private (NAAR and CAN) sponsors

Project type	Public		Private	
	1997–2001	2002–2006	1997–2001	2002–2006
Brain/behavior	93	110	82	209
Genetics	30	67	33	90
Environment	19	16	13	44
Epidemiology	13	20	4	6
Diagnosis	9	30	14	47
Treatment	29	56	13	34
Family/services	2	9	0	2

Note: Projects with multiple themes are counted multiple times

NIH National Institutes of Health; *NAAR* National Alliance for Autism Research; *CAN* Cure Autism Now

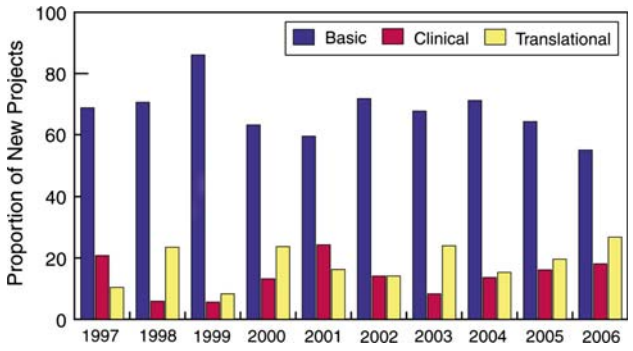

Fig. 2 Proportion of new US autism research grants with a theme of basic science, (i.e., brain and behavior, genetics and environmental causes), clinical research (i.e., treatment, diagnosis, epidemiology, and family and services), and translational research (i.e., at least one basic code and one clinical code)

$p = 0.029$). There is no significant change in the proportion of clinical research projects.

A closer look at the funding profiles of NIH and the private sponsors (i.e., NAAR and CAN) reveals that the average 1-year decrease in the proportion of basic science projects is similar and statistically significant for both sponsors (NIH, O.R. $= 0.90$, $z = -2.75$, $p = 0.006$ and private sponsors, O.R. $= 0.89$, $z = -2.64$, $p = 0.008$). Furthermore, the proportion of newly funded clinical research projects by NIH increased significantly by 11% per year ($z = 2.15$, $p = 0.032$), whereas, the proportion of translational projects funded by private sponsors increased by 25% per year ($z = 3.48$, $p = 0.001$). Overall, the NIH had a higher percentage of translational (28%) and clinical research (20%) projects from 1997 to 2006 compared to the private sponsors, while private sponsors had a higher percentage of basic research (74%) ($p < 0.001$).

Discussion

This study demonstrates a dramatic increase in funding for ASD from 1997 to 2006 that is distributed across research projects and programs in all major research categories: basic, clinical, and translational research. The trends are characterized by increased rates in the absolute number of basic research projects, but proportionally decreased rates over time. We also observed diverging trends between funding agencies. The data for NIH reflect a significant increase in funding for clinical research, whereas the data for private sponsors reveal a significant increase in funding of translational research. The focus of newly funded projects within basic sciences is dominated by brain and behavior, and genetics research, regardless of whether the funding is provided through federal agencies or parent advocacy groups.

Public and Private Funding

The trends we have demonstrated coincide with the strong political momentum on behalf of people with autism that emerged in the mid-1990s that effectively promoted public research programs, interagency committees and the establishment of the first US congressional coalition on autism research. These events include the congressionally mandated meeting on the state of autism research in 1995, the Children's Health Act of 2000, and the establishment of the Autism Research Network developed by the NIH. This network consisted of the Collaborative Programs of Excellence in Autism (CPEA) and Studies to Advance Autism Research and Treatment Centers (STAART). In parallel the Center's for CDC established the regional centers of excellence for ASD and other developmental disabilities that make up the Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) Network. The CDC CADDRE Network then established the Study to Explore Early Development (SEED), a 5-year, multi-site collaborative study of risk factors for ASD (CDC 2007c). The establishment of these programs and others account for the significant increase in NIH clinical research. We note that funding for the STAART Network and the CPEA was consolidated in 2007 into the Autism Centers of Excellence (ACE) program (Department of Health and Human Services 2006) to focus on the causes of autism and optimize treatment as it corresponds to the Autism Research Matrix, an explicit set of autism research goals and activities developed by the Interagency Autism Coordinating Committee (Department of Health and Human Services 2004).

Direct, large scale funding of research by advocacy groups essentially started in 1997. As our data show, the two major funding agencies, NAAR and CAN, gradually increased funding for basic science and clinical research and, especially over 2005 and 2006, translational research. These results represent the mission of Autism Speaks and the development of autism parent groups such as NAAR and CAN who are dedicated to funding biomedical research into the causes, prevention, treatment and cure for autism. For example, the primary mission of NAAR was to raise money for funding pilot grants for basic and clinical research in autism with the hope and expectation that these grants could be leveraged into greater funding from the NIH (London 1997). To date, these groups have leveraged nearly $153 million in NIH and other funding for the continuation of these scientific studies (Autism Speaks 2007e).

These groups undoubtedly strengthened public awareness for autism research. Since the merger of NAAR and CAN into Autism Speaks, the privately sponsored autism walk program throughout the US has shown record-breaking

attendance. Autism Speaks also started an array of new ways of raising research funds and awareness of the rising prevalence of ASD. The demands by these advocacy groups to enhance funding of autism research, especially in the areas of treatment and environmental factors, both through their lobbying efforts in Congress and their own research initiatives has shifted the landscape of research priorities in the US. Furthermore, these groups supply invaluable biomedical research materials such as DNA (Geschwind et al. 2001) and brain tissue to enhance the basic research agenda (Brimacombe et al. 2007). Thus, the landscape of autism research is changing because of the involvement of the private sector, placing advocates at the table of research priority decision-making.

Research Implications

Funding of grant proposals in both the private and the public sector is based on the peer review process. Experts in a given field read and score grant proposals and funding decisions are based on these recommendations. Requests for Applications (RFA) by funding agencies encourage scientists to submit application with a focus on a specific area. From 1996 to 2005, NIH released 15 RFAs with "autism" in its title (http://grants.nih.gov/grants/guide/). Of these, based on our definitions, six had a focus on translational, three on clinical, and five on basic sciences. In 2006, eight RFAs were published, seven of these were translational and one clinical. This clearly shows an increase in RFAs specific to autism and a shift towards conducting translational research. Our results suggest that the number of funded grants in clinical and translational research deemed worthy for funding has increased over the last decade. This trend in the science of autism is consistent, if not due to, political lobbying and independent funding of US advocacy groups. Despite this increase, the majority of new projects still focus on basic research. This may be understood in the context of remarks by Jon Shestak, a co-founder of CAN, at the 2007 International Meeting of Autism Research who stated: "we've come really far, but we haven't come far enough" (Shestak 2007).

The understanding of mechanisms underlying autism is still in its infancy and the possibilities for clinical research therefore remain limited. Pharmacological agents that have been tested clinically affect only the secondary symptoms such as depression or anxiety. The core problems associated with abnormal communication and social behaviors remain unaffected. Currently, there is no biological diagnosis for the disorder, no genetic test, no neurological circuits, no feasible animal models, and thus limited tools to develop effective new treatments.

Funding of clinical research is only one of many challenges facing the translation of basic science into clinical practice. The Clinical Research Roundtable at the Institute of Medicine also identified the growing need for research study participants, the lack of informational systems, and the shrinking clinical research workforce (Sung et al. 2003). Some of these issues are being addressed through the development of the Interactive Autism Network (IAN), for example, a project designed to accelerate the pace of autism research by linking researchers with families. This clinical resource was developed by the Kennedy Krieger Institute and funded by Autism Speaks to serve as an online research data set and registry for autism research.

In order to bridge the gap between basic science and clinical research, new research collectives will be necessary, including initiatives that support translational research. This type of research will involve the communication between clinicians and basic researchers whose collaborative work spans biology and etiology, diagnosis, prevention, treatment, and outcomes of ASD. Given the force of advocacy and the importance of the voice of all stakeholders, this collaboration can only be successful with the inclusion of partnerships with individuals with ASD and advocates of autism research. Parent-professional partnerships developed by groups such as NAAR and CAN have already changed the face of autism both socially and scientifically. The Autism Speaks Clinical Trials Network is an example of the type of translational research that aims to quickly bring promising new therapies to patients. Other emerging translational studies such as those funded by the government sector (e.g., Autism Spectrum Disorder Research Program (ASDRP) Clinical Partnership Award of the Department of Defense) and other advocacy groups such as the Autism Society of America Treatment-Guided Research Initiative (Herbert 2008) will serve to inspire innovative collaborations between those who investigate the fundamental processes in the mind, brain, and behavior with clinicians who treat and work with individuals and families with autism. The close alignment between basic and clinical research and researchers and clinical stakeholders will truly enable the translation of *research into practice* and *practice into research* (Rutter 2005).

Limitations

The present study was restricted to research grants funded by the NIH, NAAR (Autism Speaks) and CAN. Many other organizations such as the US Department of Education and the Agency for Health Care, Research and Quality were not included, which are more likely to fund research application, service and practice. Furthermore, other advocacy groups such as the Simon's Foundation, and the Doug Flutie Jr. Foundation for Autism, Inc., as well a number of pharmaceutical companies that support clinical research

trials, were not included in this analysis. Currently, there is no consistent, searchable database available that can be used to track funding trends over long periods of time of both private and public funding institutes. The present study was also hampered by the unavailability of public access to certain types of data concerning research funding. Although the NIH reported spending $108 million in 2006 alone on autism research (NIH 2007a) and the private sponsors spent $80 million collectively from 1997 to 2006, we were unable to obtain specific project dollar amounts and none were provided in the public databases. Thus, this study considers only the total number of projects and is not a reflection of the total dollar amount spent. The information available for research proposals funded by parent advocacy groups was also limited. Another potential limitation of the current study is the exclusion of some NIH grants, including fellowship research, career, and trainee grants. These grants account for approximately 16% of funded grants excluded from this analysis. However, exclusion of these grants is unlikely to alter the conclusions of this study given the extremely large gap between funding for basic and clinical research. We believe that if this gap is bridged, opportunities for improving the lives of peoples with ASD and their families will be far more substantial than they are in this current fractured research environment.

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