NIH & AUTISM: A Case Study in Barriers to Progress in Environmental Medicine

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Introduction

Medical practice for chronic illnesses has been slow to integrate the etiological principle that most human disease has an environmental component.[1] Chronic disease medicine emphasizes diagnosis, intervention after symptom onset, and finding 'disease genes'. The environmental health disciplines emphasize pollution reduction and environmental remediation. Neglect of environmental considerations in healthcare for specific diseases has negative consequences by perpetuating preventable conditions and hindering development of effective treatments.

Autism is a case in point. Autism spectrum disorders now affect 1 in 150 children and cost billions of dollars in lifetime care. Despite evidence of autism's environmentally-induced underpinnings and resulting alterations in multiple organ systems that are not necessarily developmentally determined,[2] a "brain disorder/genetic heritability" paradigm prevails. Autism healthcare continues to be managed by psychiatric/behavioral professionals who carry the assumption that autism is a lifelong condition requiring services centered around diagnosis, therapies, and behavioral interventions that have the goal to merely improve the functioning of a defective organism rather than promote the recovery of an injured child.[3]

Progress in the translation of environmental findings into the clinic is largely determined by the priority assigned by grant providers in the research field in question and how they allocate funding resources between different research domains and clinical translation efforts. The largest and most influential entity that sets research funding priorities is the National Institutes of Health. An examination of NIH practices can inform the question of why certain fields and approaches receive resources to advance their theories while others do not. Recent Congressional initiatives on autism research offer an opportunity to examine NIH practices that impact environmental medicine.

In 2006, Congress requested $744 million to be spent over 5 years for basic and clinical research on autism, primarily by NIH. The Interagency Autism Coordinating Committee (IACC) led by NIMH was charged with creating a strategic plan (SP) for autism research to guide funding decisions. The draft SP nears finalization and a vote for approval in November 2008. We reviewed past autism research spending practices at NIH as well as future priorities reflected in the draft SP.[4] We wished to assess how past choices by NIH have impacted current clinical practice, how past priorities might impact future research, and what factors influence choices regarding environmental science.

Methods

Aim 1: Analysis of past autism research priorities at NIH

- Searched NIH CRISP database of all grants (1980-2007) in autism spectrum disorders scoring 11-100
- Used the 4850 records obtained to create new database using crawler and screen scraper techniques
- Converted data into Excel Spreadsheet and
- Imported records into Latent Semantic Analysis (LSA) tool called Themescape for vectorial semantic clustering analysis and visualization

Aim 2: Analysis of future autism research priorities at NIH

- Identified NIH-invited participants in SP development and implementation
- Calculated total spending and allocations by main research category and analyzed text in draft SP to characterize NIH strategic intent

Results

Aim 1: analysis of past autism research priorities at NIH

- Grants identified as related to "autism" grew rapidly during the 1990s, but then total funding stagnated
- NIEHS is not active in autism funding (Fig.1) and environmental researchers are not among leading grant recipients (Fig.2)
- Genetics, diagnosis/description, and behavior dominate in funding (Figs.3&4)

Aim 2: analysis of future autism research priorities at NIH

- Acknowledgement of alarming rise in prevalence from environmental triggers is absent
- Proposed spending is below Congressional request and below reported 2007 levels (Fig.5)
- NIEHS and environmental stakeholders marginalized; genetics organizations given prominent voice
- Genetics-only research budget remains dominant in Etiology domain (Fig.6)
- Diagnosis allocations equal those for treatment (Fig.6)

Conclusions

Autism is a serious chronic condition with recognized environmental etiology not reflected in mainstream medical practice. Analyses of trends in NIH autism spending demonstrate that research priorities remain unchanged, with continued underfunding and domination by genetic, diagnostic, and behavioral disciplines. Since past NIH priorities are reflected in current mainstream clinical practice, it is likely that future clinical practice will mirror the NIH SP priorities. Assuming the draft SP is approved as is, clinical care will continue to neglect environmentally-informed treatment approaches and will be inadequate to reduce the steep rise in autism prevalence.

A noticeable factor driving these observations is the reluctance of NIH to fully include environmental representatives while promoting advocates of the established brain disorder/genetic heritability paradigm. A commitment by environmental scientists to insert themselves into NIH discussions at critical junctures like strategic plan development may go a long way to removing barriers to progress in integrating environmental medicine into mainstream practice.

1. Olden, K. Environmental Health Research Challenges. In *Managing for Healthy Ecosystems*. David Rapport, Bill L. Lasley, Dennis E. Rolston, N. Ole Nielsen, Calvin O. Qualset, Ardeshir B. Damania, Eds. CRC Press, 2003.
2. Szpir, M. Tracing the origins of autism: a spectrum of new studies. *Environmental Health Perspectives*. 2006; 114(7):412-7.
3. See, for example, (a) the announcement for a new autism center at UMDNJ-RWJ, http://www.umdnj.edu/about/news_events/releases/07/r090507_Austism_Center.htm. (b) the website for the autism center at the University of Missouri, http://thompsoncenter.missouri.edu/. (c) the website for the Kennedy Krieger autism center, http://www.kennedykrieger.org/kki_2nd_inside.jsp?pid=12
4. NIH Draft IACC Strategic Plan of August 15, 2008. Available at http://www.nimh.nih.gov/research-funding/scientific-meetings/recurring-meetings/iacc/strategic-plan/2008/iacc-strategic-plan-august-2008.pdf.

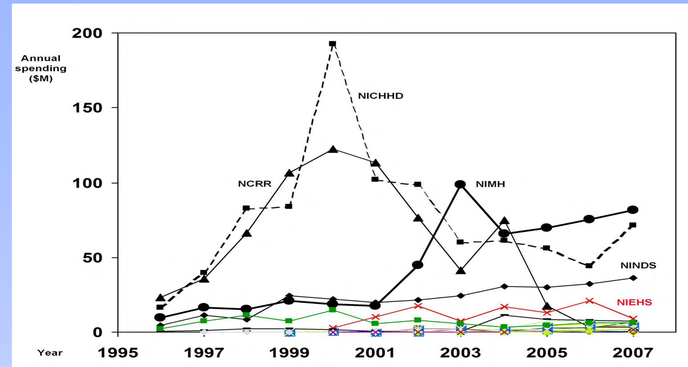

Fig 1. Past funding was mostly through NIMH & NICHD, with NIEHS weakly represented.

Rank	Principal Investigator	# of grants	Field of research
1	PIVEN, JOSEPH	55	Genetics (inc. CLSA)
2	DAWSON, GERALDINE	52	Genetics, neurobiology, early diagnosis
3	AMARAL, DAVID	51	Neurobiology
4	COHEN, DONALD	50	Neurochemistry, mental retardation
5	VOLKMAR, FRED	49	Genetics, neurobiology, SSRIs
6	TAGER-FLUSBERG, HELEN	49	Language
7	PERICAK-VANCE, MARGARET	48	Genetics
8	SIGMAN, MARIAN	47	Social and communication deficits
9	MINSHEW, NANCY	47	Neurobiology
10	RODIER, PATRICIA	44	Genetics and brainstem injury
11	COURCHESNE, ERIC	44	Neuroanatomy and audio/visual processing
12	LORD, CATHERINE	41	Diagnostics
13	ROGERS, SALLY	39	Definition of autism phenotype
14	NAIDU, SAKKUBAI	36	Rett's Syndrome
15	LANDA, REBECCA	33	Familial phenotype, neurobiology
16	GLAZE, DANIEL	33	Rett's Syndrome
17	REISS, ALLAN	29	Fragile X Syndrome
18	MCDOUGLE, CHRISTOPHER	28	Psychopharmacology
19	CAMPBELL, MAGDA	28	Psychopharmacology
20	MCMAHON, WILLIAM	27	Genetics
21	PESSAH, ISAAC	27	Environmental factors, neurotoxicology
22	COOK, EDWIN	27	Genetics
23	KOEGEL, ROBERT	25	Parent intervention, training
24	SCHREIBMAN, LAURA	25	Parent intervention, training
25	LOVELAND, KATHERINE	24	Neuroanatomy, language and communication
26	FOLSTEIN, SUSAN	24	Genetics, familial phenotype
27	HOLLANDER, ERIC	24	Neurochemistry, psychopharmacology

Fig 2. Genetics, diagnosis/description, behavioral investigators were past top grantees. Only one environmental scientist was funded.

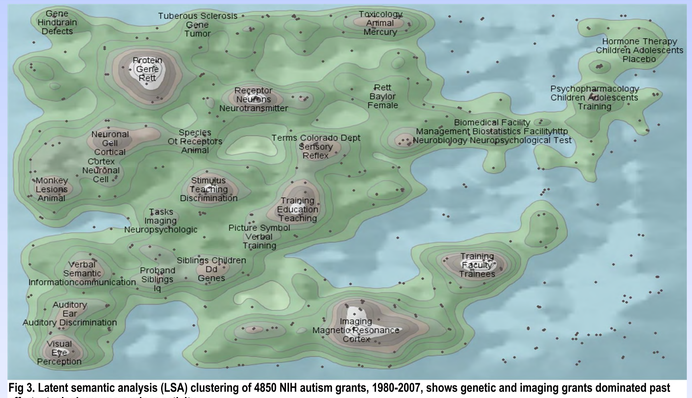

Fig 3. Latent semantic analysis (LSA) clustering of 4850 NIH autism grants, 1980-2007, shows genetic and imaging grants dominated past efforts; toxicology was a minor activity.

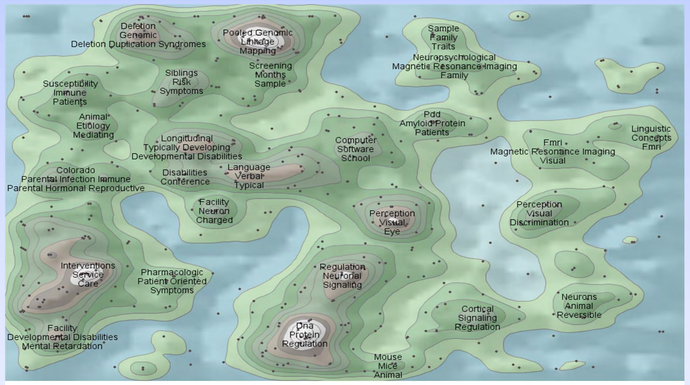

Fig 4. In most recent clustering of past grants (1000 grants from 2005-2007 only), environment is absent.

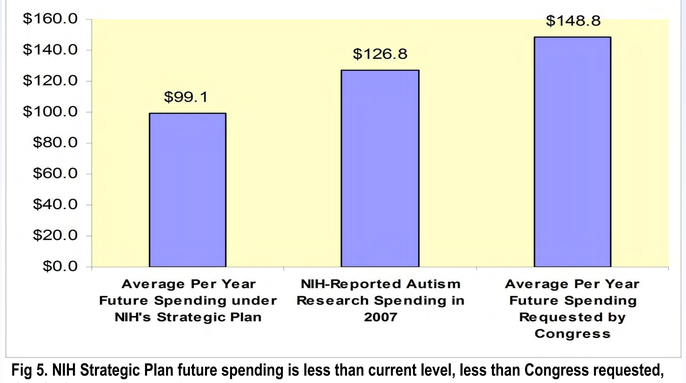

Fig 5. NIH Strategic Plan future spending is less than current level, less than Congress requested, despite increase in prevalence.

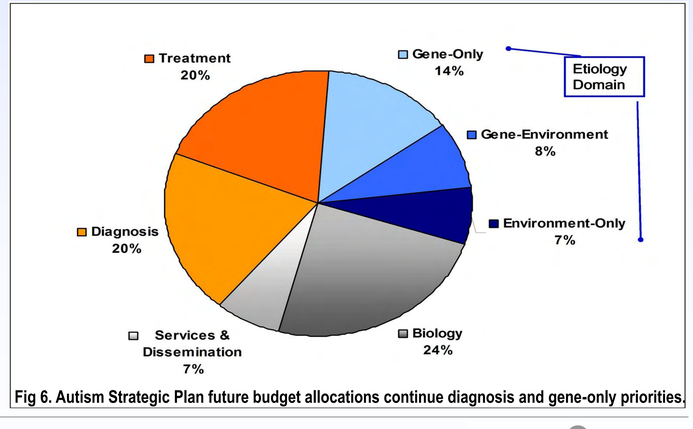

Fig 6. Autism Strategic Plan future budget allocations continue diagnosis and gene-only priorities.

SafeMinds is a non-profit organization focusing on mercury's role in autism, an environmental theory deserving attention and resources in light of increased human exposures to mercury and the rising frequency of autism spectrum disorders. SafeMinds advocates for social awareness and scientific research into environmental factors in autism, funds external research and conducts internal analyses on related topics.

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Sensible Action For Ending Mercury-Induced Neurological Disorders