

A COMPREHENSIVE PLAN TO STUDY AND ADDRESS THE GLOBAL ISSUES AND CHALLENGES OF AUTISM

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Abstract

This paper includes several related parts: (1) An intellectual/normative framework that challenges the research and policy-making community to study and address the complex and poorly understood world of autism. (2A) A visualization or graphic road map of the relevant variables that comprise the autism realm: "The Autism Life Matrix." (2B) A longitudinal representation of "what" is involved (i.e., a guide for learning) and "how" to address autism challenges (i.e., a guide for doing or acting) for each stage of an individual's life-cycle. (3) A proposal to fund, regularly collect, analyze, and report quantitative and qualitative survey data from the United States and world-wide on specified parameters among those touched by autism through their family or vocation. (4) A description of the proposed development of an empirically based autism algorithm or equation using econometric analysis of survey data as well as case studies. (5) A plan to establish an international autism think tank or institute (as part of a consortium of universities reflecting an interdisciplinary orientation) to design, coordinate, carry out, and report research on the efficacy of various diagnostic and treatment modalities as well as study the individual and societal costs of autism over the life cycle, including case studies. This institution will maintain a museum, a library, and a repository or computerized data storage center of all of the world's data, research and reporting on autism as well as a world-wide registry of all those on the autism spectrum and their associated caregivers. It also will provide autism medical evaluation, treatment plans, and patient care as well as train doctors and nurses specializing in this area. It will maintain a web site, produce documentary/educational films and videos, and publish newsletters, curriculum guides, manuals, and specialized materials for educators, for those trained to serve the autistic community, and for the families of those with the diagnosis of autism spectrum disorder. It also will include a conference center that will host and broadcast periodic world-wide conferences, provide housing for those in residence, and feature a day-care facility with a professional staff. A brief account of the reality of living

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with autism also is presented. (6) A summary of a proposal to design, research, write, publish, and distribute a medical school textbook on the autistic brain and its evaluation and treatment. (7) A plan to educate the general public around the world (through mass media such as film and television) so that society will embody a more compassionate understanding of autism and manifest a collective willingness to devote more resources to addressing the issues and needs of those in the autism community. (8) A brief summary of a separate, detailed proposal with a budget to obtain sufficient funding to implement all the steps needed to meet the goals and objectives of this comprehensive effort.

Economics of autism 2. Medical textbook mapping the autism brain 3. Repository of data

Topic Groups: policy, economics over the lifetime

PART 1: AN INTELLECTUAL CHALLENGE FOR THE RESEARCH AND POLICY-MAKING COMMUNITY AND A VISION FOR RESOLVING THE MYSTERIES OF AUTISM SPECTRUM DISORDER.

This entire presentation is intended to be an intellectual challenge for the research and policy-making community to study, address and integrate a series of complex social problems and the societal costs associated with the individuals, families and institutions (e.g., schools, social agencies, government agencies, health care providers, employers, emergency responders such as fire and police departments, media and public perceptions and opinions, insurance companies, pension and retirement plans, financial planners and advisors, etc.) touched directly and indirectly by those on the autism spectrum. [See: "Autism Spectrum Disorder" in American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders: DSM-5, Fifth Edition (Arlington, VA.: American Psychiatric Association, 2013), pp. 31-32 and 50-59 and Uta Frith, Francesca G. Happé, David G. Amaral, and Stephen T. Warren, "Autism and Other Neurodevelopmental Disorders Affecting Cognition," in Principles of Neural Science, Fifth Edition, Edited by Eric R. Kandel, James H. Schwartz, Thomas M. Jessell, Steven A. Siegelbaum, and A. J. Hudspeth (New York, N.Y.: The McGraw-Hill Companies, Inc., 2013), Chapter 64, pp. 1425-1440. For a discussion on whether the prevalence of autism is increasing and the role of shifting diagnoses, heightened awareness, and possible environmental causes, see: Karen Weintraub, "Autism counts," Nature, Vol. 479, November 3, 2011, pp. 22-24. A special issue on neuroscience, "The autism enigma: sorting fact from fiction," was published on-line on November 2, 2011 at <http://www.nature.com/news/specials/autism/index.html>. See also, "Autism spectrum," which discusses classification, characteristics, causes, pathophysiology, diagnosis, management (i.e., therapies), epidemiology, history, and society and culture at https://wikipedia.org/wiki/Autism_spectrum and Simon Makin, "What Really Causes Autism," Scientific American Mind, Vol. 26, No. 6, November/December 2015, pp. 56-63 which concludes that autism is primarily a complex genetic disorder. For a comprehensive contextual history of autism, with many stories of children and adults who are on the autism spectrum and their families, clinicians, and the researchers who study them, see: Steve Silberman, NeuroTribes: The Legacy of Neurodiversity (New York, N.Y.: Penguin Random House, 2015). See also: Henry Markram, Tania Rinaldi and Kamila Markram, "The Intense World Syndrome – an alternative hypothesis for autism," frontiers in neuroscience, Volume 1, Issue 1, November 2007, pp. 77-96 and on-line at <http://www.frontiersin.org/Neuroscience/10.3389/neuro.01.1.1.006.2007/full>, Gary Greenberg, The Book of Woe: The DSM and the Unmaking of Psychiatry (New York, N.Y.: Penguin Books Ltd., 2013), especially pp. 187-190, 196-200, and 296-299, Pam Belluck and

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Benedict Carey, "Psychiatry: New Guide Falls Short, Experts Say," The New York Times, May 7, 2013, pp. A1 and A15, Allen Frances, Saving Normal: An Insider's Revolt Against Out-of-Control Psychiatric Diagnosis, DSM-5, Big Pharma, and the Medicalization of Ordinary Life (New York, N.Y.: HarperCollins Publishers, 2013), Dwight Garner, "Two Pleas for Sanity in Judging Saneness," The New York Times, May 2, 2013, p. C1, and Martha Stout, "The Pernicious Politics of the DSM-V: A brilliant look at the medicalization of misery," The New Republic, May 8, 2013 also on-line at <http://newrepublic.com/article/113097/gary-greenberg-book-woe-reviewed-martha-stout>. For a powerful and fascinating investigation about family and the intense challenges of parenthood, see Andrew Solomon, Far from the Tree: Parents, Children, and the Search for Identity (New York, N.Y.: SCRIBNER, A Division of Simon & Schuster, Inc., 2012), especially Chapter V, "Autism." See also: Chantal Sicile-Kim, Autism Spectrum Disorder: The Complete Guide to Understanding Autism (New York, N.Y.: A Perigee Book Published by the Penguin Group, Revised Edition, 2014).]

The CDC reports that about 1 percent of the world population has autism spectrum disorder, including about 3.5 million Americans with an associated annual cost for services of \$236-262 billion (\$175-196 billion for adult services, compared to \$61-66 billion for children). [See facts and statistics summarized by The Autism Society: <http://www.autism-society.org/what-is/facts-and-statistics/>.] A key study suggests that autism spectrum disorder diagnoses sometimes change due to misdiagnosis, maturation, or treatment. [See: Stephen J. Blumberg, et al., "Diagnosis lost: Differences between children who had and who currently have an autism spectrum disorder diagnosis," Autism, September 26, 2015, pp. 1-13 at: <http://www.aut.sagepub.com/content/early/2015/10/14/1362361315607724.full.pdf+html>.

Because this webpage is sometimes not available, we suggest that readers who want a hard copy contact the lead author at National Center for Health Statistics, Centers for Disease Control and Prevention, 3311 Toledo Road, Hyattsville, MD. 20782, USA or via e-mail: sblumberg@cdc.gov.] Initially, we will display or visualize a simplified graphic summary of the eight autism topics or sections addressed in this paper. This will be done so that all the interrelated parts can be understood as an integrated approach to developing or expanding the scope and nature of the autism realm of concerns and how to comprehensively deal with these components so that a major shift can be made in the way humanity deals with this set of problems. As the empirical results of this endeavor are examined and evaluated, the resulting insights will lead to adjustments and modifications of the view or guiding intellectual/normative framework so that it will include newly understood relationships.

PART 2A: A CONCEPTUAL ROAD MAP: THE AUTISM LIFE MATRIX.

A hands on conceptual visual road map (called "The Autistic Life Matrix") will be produced that will help people involved to put everything in perspective, get a handle on this subject, and reduce their anxiety and feelings of being overwhelmed by all the pieces of this formidable puzzle and life journey. In other words, each component forms the basis for a collective atlas of the scope, nature and interrelationship of all the hundreds of relevant variables that should be understood in order to plan and provide for a sustainable, healthy life associated with these unique characteristics and needs. [Our visualization or chart was partly inspired by "The Self-Reliance Matrix" (addressed to ordinary or average folks) published on September 4, 2015 by Dan West of Walden Labs. See <http://waldenlabs.com/161-aspects-of->

self-reliance/. In contrast, autistic individuals often require full-time supervision and care. Sometimes they can be trained to become more self-reliant and independent.]

PART 2B: A LONGITUDINAL VISUALIZATION OF DATA AT EACH STAGE OF AN AUTISTIC PERSON'S LIFE.

We will produce a temporal or longitudinal visual representation of “what” is involved (for learning) and “how” to deal with these challenges (for taking action or doing) for each stage of an autistic individual's life. These graphic displays or visualizations are meant to empower the viewer so that he or she may systematically render disparate and complex data on all aspects of autism into coherent, integrated insights and understanding. We want to stimulate and develop visual thinking. Our goal is to engender the development of a synthesis of knowledge about autism at the micro (individual), meso (local), and macro (global) level. [See: the Cyberinfrastructure for Network Science Center at Indiana University in Bloomington at <http://cns.iu.edu/>. See also Katy Borner, Atlas of Knowledge: Anyone Can Map (Cambridge, Mass.: MIT Press, 2015) and <http://scimaps.org/atlas2>.]

PART 3: A PROPOSAL FOR WORLD-WIDE AUTISM SURVEY DATA COLLECTION.

We propose to fund world-wide surveys to collect needed data on the specified parameters being discussed here. In addition to our employing domestic academic survey research centers such as the Survey Research Center at The University of Michigan in Ann Arbor, Michigan or the National Opinion Research Center at The University of Chicago, senior research and management officials at the Gallup World Headquarters in Washington, D.C. have agreed to field added questions about autism in their world-wide surveys if we can procure the necessary funding. In order to provide depth and nuance to any quantitative survey results we aim to balance such data with qualitative insights that are uncovered via individual perspectives in interviews. [See: Ilana Ron Levey and John Timmerman, “More Data Doesn't Always Mean Better Insights,” at http://www.gallup.com/businessjournal/186455/data-doesn-always-mean-better-insights.aspx?utm_source=alert&utm_medium=email&utm_content=morelink&utm_campaign=syndication.]

PART 4: A PROPOSAL FOR DEVELOPING AN ECONOMETRIC MULTIPLE REGRESSION MODEL TO STUDY INDIVIDUAL AND SOCIETAL COSTS OF AUTISM AT EACH STAGE OF THE LIFE CYCLE AND FOR COLLECTING CASE STUDIES OF AUTISTIC FAMILIES OVER TIME.

We describe an autism algorithm or equation as part of a comprehensive research design proposal for an econometric multiple regression model that will use Bayesian statistics to calculate the probabilities for various estimated individual and societal costs at each stage (and in the aggregate) of the life cycle of an autism spectrum individual. Causal parameters will be explored in structural and reduced form equations. Regression coefficients will be studied in forecasting equations. Sensitivity analysis will be performed on the data (i.e., estimating “impact” regressions over various subsets of data, also referred to as sub-regressions or narrowly defined subgroups). Also included will be a case study of a real family over a period of several years. It will specify tangible and intangible financial (fiscal) costs, emotional/psychological costs, health/physical/medical costs (including evaluation and

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testing such as brain scans), therapy, medications, special diets, the costs of support animals, and related transportation costs. [A study reported in 2014 found that the cost of autism over the lifespan in the United States is about \$2.4 million for a person with an intellectual disability and \$1.4 million for an individual without such a disability. See Ariane V. S. Buescher, et al., “Costs of Autism Spectrum Disorders in the United Kingdom and the United States,” JAMA Pediatrics, Vol. 168, No. 8, August 2014, pp. 721-728 or on-line at <http://archpedi.jamanetwork.com/article.aspx?articleid=1879723> and the link to the web site of The Autism Society provided above in Part 1.] In addition, a series of recorded and transcribed interviews will be made with all members of the family, medical professionals associated with the case, social workers, teachers, etc. If funded, it is our intent to publish a series of articles and then an anthology of such case studies along with a documentary film comprised of video recordings made by autistic spectrum families all over the world.

Methodologically, we approach this effort with the normative perspective of those who see an inappropriate societal insensitivity or dysfunction, problem, wrong, injustice, error, damage, or injury (inflicted upon the autism community) much like those who litigate as antitrust attorneys who use empirical econometric findings and analysis to estimate damages inflicted upon a certified class due to anticompetitive acts. [See: American Bar Association Section of Antitrust Law, Econometrics – Legal, Practical, and Technological Issues, Second Edition, 2014. See also, Jeffrey M. Wooldridge, Introductory Econometrics: A Modern Approach (Mason, OH.: South-Western CENGAGE Learning, Fifth Edition, 2013) and Barbara Bund Jackson, Multivariate Data Analysis: An Introduction (Homewood, Illinois: Richard D. Irwin, Inc., 1983), “APPENDIX A: Bayes’ Theorem and Likelihood,” pp. 221-231. Also of key relevance here are the following discussions: David L. Vaux, “Know when your numbers are significant,” Nature, Vol. 492, Issue No. 7428, 13 December, 2012, pp. 180-181 and Megan D. Higgs, “Do We Really Need the S-word [significant]?” American Scientist, Vol. 101, January-February, 2013, pp. 6-9. For an orientation to this subject, see: Steven S. Skiena, The Algorithm Design Manual, (New York: Springer-Verlag New York, Inc., 1998) and Thomas H. Cormen, Charles E. Leiserson and Ronald L. Rivest, Introduction to Algorithms, (Cambridge, Massachusetts: The MIT Press and New York: McGraw-Hill Book Company, 1990).]

PART 5: A PLAN TO ESTABLISH AN INTERNATIONAL AUTISM THINK TANK OR INSTITUTE THAT WILL: CONDUCT RESEARCH, MAINTAIN A MUSEUM, A LIBRARY, A REPOSITORY OR COMPUTERIZED DATA STORAGE CENTER, AND A WORLD-WIDE REGISTRY OF THOSE ON THE AUTISM SPECTRUM, PROVIDE AUTISM MEDICAL EVALUATIONS AND PATIENT CARE, TRAIN DOCTORS AND NURSES, MAINTAIN A WEB SITE, PRODUCE FILMS AND VIDEOS, PUBLISH MANUALS AND NEWSLETTERS, TRAIN AUTISM CAREGIVERS AND OTHERS, MANAGE A CONFERENCE CENTER, HOST WORLD-WIDE CONFERENCES, AND PROVIDE HOUSING AND RELATED FACILITIES.

We present an explicit plan to establish an international autism think tank or institute (ideally, affiliated with a major university and its medical school) that will serve as the institutional base for implementing and coordinating these efforts. Perhaps a formal consortium of several universities could work together in order to enable an interdisciplinary approach to become truly viable. A critical mass of the world’s intellectual resources must be applied in order to successfully address all the dynamics of this global conundrum. [In order to see exactly how

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fruitful interdisciplinary collaboration (i.e., genuine integration) actually is able to deliver tangible outcomes in a real situation (especially between the social and biophysical sciences), see: Rebekah R. Brown, Ana Deletic and Tony H. F. Wong, "How to Catalyse Collaboration," *Nature*, Vol. 525, No. 7569, 17 September, 2015, pp. 313-317. This article is part of a very instructive special issue of *Nature* called "INTERDISCIPLINARITY." For an extensive discussion of six pairs of interdisciplinary studies and a proposed "taxonomy" that provides a conceptual vocabulary to assist the consideration of these matters, see Harvey J. Graff, *Undisciplining Knowledge: Interdisciplinarity in the Twentieth Century* (Baltimore, MD.: Johns Hopkins University Press, 2015).]

Also of considerable interest is an Executive Order issued by President Barack Obama on September 15, 2015: "Using Behavioral Science Insights to Better Serve the American People." [See: <https://www.whitehouse.gov/the-press-office/2015/09/15/executive-order-using-behavioral-science-insights-better-serve-american> and Binyamin Appelbaum, "Behaviorists Show U.S. How to Nudge," *The New York Times*, September 30, 2015, pp. B1 and B2.] In addition, one should be sure to note: "Fact Sheet: President Obama Signs Executive Order; White House Announces New Steps to Improve Federal Programs by Leveraging Research Insights," which is a press release summary of a thorough report about ongoing executive team efforts. [For the full report, see: Executive Office of the President, National Science and Technology Council, "Social and Behavioral Sciences Team: 2015 Annual Report," Washington, D.C., 20502, September 2015 on-line at https://www.whitehouse.gov/sites/default/files/microsites/ostp/sbst_2015_annual_report_final_9_14_15.pdf or <https://www.canfieldpress.com/the-social-and-behavioral-sciences-team-annual-report-for-2015>.] The fact sheet includes the following list of twenty participating and contributing research centers and organizations: The Behavioral Science & Policy Association (BSPA), The Brookings Institution, Carnegie Mellon University's Center for Behavioral Decision Research, Duke University's Behavioral Science & Policy Center, Harvard University's Behavioral Insights Group, ideas42, MIT's J-PAL North America at MIT, The Kahneman-Treisman Center for Behavioral Science and Public Policy at Princeton University, Stanford University's Longevity Center and Institute for Research in Social Science, University of California, Berkeley's Goldman School of Public Policy, University of California, Los Angeles' Interdisciplinary Group in Behavioral Decision Making, University of California, San Diego's Rady School of Management, The University of Chicago Booth School's Center for Decision Research, The University of Colorado Boulder's Center for Research on Consumer Financial Decision Making, The University of Iowa's Tippie College of Business, The University of Michigan's Gerald R. Ford School of Public Policy, The University of Pennsylvania's Center for Health Incentives and Behavioral Economics at the University of Pennsylvania, The University of Southern California's Dana and David Dornsife College of Letters, Arts and Sciences, The University of Toronto's Rotman School of Management, and Yale University's Center for Customer Insights. This list could serve as the foundation for efforts at forming the consortium of institutions to support and house an Autism Research Center or Institute. [See: <https://www.whitehouse.gov/the-press-office/2015/09/15/fact-sheet-president-obama-signs-executive-order-white-house-announces>.]

One specific example from the list immediately above exemplifies the potential utility of such cooperation and how it could help support the proposed Autism Institute: ideas42. [See: <http://ideas42.org/about-us/>.] Doug Palmer, a Senior Associate at ideas42 who works on projects with the City of Chicago, is someone at the organization with whom we would work. Their behavioral diagnosis and design process emphasizes: refining problem definitions,

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gathering data, identifying actionable bottlenecks, brainstorming, focusing on and piloting scalable interventions, and using random assignment or other experimental frameworks. [See: Lashawn Richburg-Haryes, et al., “Behavioral Economics and Social Policy: Designing Innovative Solutions for Programs Supported by the Administration for Children and Families (of the Office of Planning, Research and Evaluation, U.S. Department of Health and Human Services),” OPRE Report No. 2014-16a, April 2014 and on-line at http://www.ideas42.org/wp-content/uploads/2015/05/bias_final_full_report_rev_15_14.pdf.]

Thus, as a reminder for ourselves and for our readers about the possible range of disciplines that could focus on these ideas, here is a list of potential subjects or fields of study as well as foci for curators, designers, cultural critics, and intellectual provocateurs in general: information/library science, epistemology, data storage and computer science, philosophy, comparative religious studies, history, mathematics, statistics, research methods (e.g., survey design and sampling), economics, econometrics, nursing, medicine, neurology, epidemiology, pharmacology, pharmacogenomics (the study of variation that influences how an individual responds to a particular drug), psychiatry, behavioral therapy, pediatrics, geriatrics, psychology, craniosacral therapy (to relieve tension and achieve relaxation), sleep science, anthropology, sociology, social work, political science, public administration, business, management, law, accounting, education, a variety of languages, linguistics, speech therapy, mass communication, journalism, literature, writing, music, art, architecture, biology, physiology, computational psychophysiology, cellular and molecular biophysics, genetics, epigenetics (the study of gene-environmental interactions), chemistry, physics, engineering, and climatology. [See: “100 ‘global minds’ who have crossed subject frontiers: An Italian dean has created an A to Z of interdisciplinarity,” September 30, 2015 at <https://www.timeshighereducation.com/news/100-global-minds-who-have-crossed-subject-frontiers> and Gianluigi Ricuperati, 100 Global Minds: The Most Daring Cross-Disciplinary Thinkers in the World (Dublin, Ireland: Roads Publishing, forthcoming).]

Many of the so-called relevant “problems” or “issues” associated with autistic individuals and society in general may be addressed, studied, and gain knowledge from the perspective of every one of the disciplines just listed. Each subject represents a fresh opportunity to engage in studying some aspect of the pain and suffering of this perplexing predicament so that there is a reasonable chance to provide relief and to manifest joy and happiness for both those who give and those who directly or indirectly receive such knowledge and assistance. By responding intellectually and emotionally to the “misfortunes” or “hardships” of others we express compassion or empathy and thus, through our kindness and generosity we are altruistic. [See: Matthieu Ricard, The Power of Compassion to Change Yourself and the World, Translated by Charlotte Mandell and Sam Gordon, (New York, N.Y.: Little, Brown and Company, 2013), Peter Singer, The Most Good You Can Do: How Effective Altruism Is Changing Ideas About Living Ethically (New Haven: Yale University Press, 2015), Christopher Boehm, Moral Origins: The Evolution of Virtue, Altruism, and Shame (New York, N.Y.: Basic Books, 2012), Oren Harman, The Price of Altruism: George Price and the Search for the Origins of Kindness (New York, N.Y.: W. W. Norton, 2010), His Holiness the Dalai Lama, How to Be Compassionate: A Handbook for Creating Inner Peace and a Happier World, Translated from Oral Teachings and Edited by Jeffrey Hopkins (New York, N.Y.: Simon & Schuster, Inc., 2011), and Daniel Goleman, A Force for Good: The Dalai Lama’s Vision for Our World (New York, N.Y.: Bantam Books, 2015).]

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In other words, dealing with autism is not an esoteric subject: everyone can and should get involved. An autistic individual may show symptoms such as persistent repetitive behavior, motor-coordination impairment, continuous impairment in reciprocal social communication and social interaction (such as avoiding eye contact), obsessive insistence on preservation of sameness, ritual and strange relations to objects, delayed cognitive development, or having meltdowns or paroxysms of rage (e.g., dropping to the ground kicking and screaming, banging their head against the wall, or other outbursts) if someone touches them. Can a bus driver, a policeman, the workers at a fast food restaurant, a school teacher, or the flight attendants on an airplane be appropriately trained to deal with such situations? Professionals may be ignorant or insensitive about their patient or client needs. For example, when a typical physician or dentist examines or treats an autistic patient they may not realize or understand that the individual (even if they are an adult) may require the presence of a parent, a caregiver, or even a service animal such as a cat while they are in the examination room. They may never consider what sort of picture books or dolls or toys such a patient might prefer while they are in the waiting room of their office. The office manager may not have a clue as to what to do if the patient has a meltdown or sudden emotional reaction. Such considerations will be addressed in the medical school textbook proposed in part 6 of this paper immediately below. It will stress that there is a critical need to openly and honestly address sensitive subjects such as adolescent dating, sexual behavior, and potential marriage inside and outside of the autistic community.

Because of the constant, daily, often mundane, unavoidable, time-consuming, frequent, complicated, and demanding vicissitudes or difficulties imposed upon a caregiver in an autistic household environment that may go on well into the adulthood of a child (including: shopping for food, cooking, feeding, medicating, prescription re-filling, bathing, grooming, dressing, laundering, cleaning, caring for a service animal, entertaining, consoling, protecting, calming, exercising, motivating, encouraging, teaching, record keeping, budgeting, planning, advocating for, finding as well as scheduling, coordinating and supervising other caregivers or assistants, arranging transportation to therapeutic appointments, and monitoring a child in order to be sure that they do not wonder off or run in front of a car), a parent (commonly a single mother) may be precluded from employment and thus suffer not only from anxiety, depression, exhaustion, burnout, and poor health, but also from severe financial deprivation and even poverty. As indefatigable and passionate advocates trying to convey the reality of living with autism, our vision is to deal with such matters for the benefit of humanity as a whole by balancing the tension between those who hold the view that we should try to change individuals with autism to be more like everyone else and those who have the alternative perspective that we should change the world to be more autism-friendly. In many respects autistic families often suffer unjustly. This is untenable. We must respect differences. Every person has an intrinsic value and should be regarded as fundamentally good rather than having the stigma of being perceived as being weak, disadvantaged or handicapped. We hope that these ideas will lead to the development of institutions, knowledge, and behavior that will greatly facilitate the resolution of these concerns instead of the prevailing continuous proliferation of ignorance and unnecessary suffering.

There are models of societal attitudes and compassionate behavior that we can look at to learn from and emulate such as the special needs services in the Netherlands, including: special schools that cater to the needs of children with autism (along with mainstream primary school attendance wherever possible), providing behavioral therapy, transportation and journey assistance, housing once they are adults, and Dutch “legislation that protects the rights of

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people with a physical, mental, emotional, or sensory impairment that ensures equal access to social, economic and transport systems and encourages full participation in society.” [See: http://www.expatica.com/nl/about/A-guide-to-special-needs-services-in-the-Netherlands_101936.html and a National Autism Network at: [http://www.landelijknetwerkautisme.nl/.](http://www.landelijknetwerkautisme.nl/)]

The institute will establish an international leadership team and an advisory board ideally with members such as Temple Grandin, an accomplished and well-known adult with autism who is a professor of animal science at Colorado State University. [One of her recent books discusses neuroimaging advances and genetic research that link brain science to behavior. See: Temple Grandin and Richard Panek, The Autistic Brain: Thinking Across the Spectrum (New York: Houghton Mifflin Harcourt, 2013). See also: Temple Grandin, Thinking in Pictures: And Other Reports from My Life with Autism (New York, N.Y.: Vintage Books, A Division of Random House, Inc., Second Edition, 2006).] The institute also will invite visiting scholars and create an endowed chair for a professor of autistic studies.

The institute will create and maintain a museum, a library, and a repository or computerized data storage center of the world’s data, research, and reporting on the autism spectrum. [It is crucial to plan for an institutional data policy, especially in regard to terms of access, intellectual property ownership and retention, and data security and privacy. See: Kristin Briney, Abigail Goben, and Lisa Zilinski, “Do You Have an Institutional Data Policy? A Review of the Current Landscape of Library Data Services and Institutional Data Policies,” Journal of Librarianship and Scholarly Communication, Volume 3, Issue 2, published September 22, 2015, available on-line at: <http://dx.doi.org/10.7710/2162-3309.1232>.] It will conduct systematic reviews and meta analyses of the autism spectrum literature in order to evaluate all published evidence (pro and con) regarding the efficacy of assessment/diagnosis methods, treatment approaches, and existing and proposed means of care. It is important to emphasize that all the data will be made available to the world’s research community (without compromising the identity of individual subjects) so that studies can be replicated and thus support the legitimacy of research findings. [See: Open Science Collaboration, “Estimating the reproducibility of psychological science,” Science, Vol. 349, Issue 6251, 28 August, 2015, p. 943 or read the full article at <http://dx.doi.org/10.1126/science.aac4716>, C. Glenn Begley, Alastair M. Buchan and Ulrich Dirnagl, “Institutions must do their part for reproducibility,” Nature, Vol. 525, Issue No. 7567, 3 September, 2015, pp. 25-27, Daniel Sarewitz, “Reproducibility will not cure what ails science,” Nature, Vol. 525, Issue No. 7568, 10 September, 2015, p. 159, Shirley S. Wang, “The Debate: Does It Help To Repeat Past Studies?,” The Wall Street Journal, October 6, 2015, pp. D1 and D2, and Raphael Silberzahn and Eric L. Uhlmann, “Many hands make tight work: Crowdsourcing research can balance discussions, validate findings and better inform policy,” Nature, Vol. 526, No. 7572, October 8, 2015, pp. 189-191. They conducted a landmark, methodologically innovative experiment to study race bias in referee decisions where, “Twenty-nine research teams reached a wide variety of conclusions using different methods on the same data set to answer the same question (about football players’ skin colour and red cards).” (*Ibid*, p. 190.)]

The institute will conduct comprehensive original research on the efficacy of various diagnostic and treatment modalities as well as study the individual and societal costs of autism over the life cycle, including case studies (discussed in Part 4 above). These studies will employ the most efficacious methods, including: randomized controlled trials,

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epidemiologic studies, cohort or longitudinal studies, case control studies (comparing people [individuals and families] with and without autism experience), and case reports.

A world-wide registry of all those on the autism spectrum and their associated caregivers will be established. This will enable those listed in the inventory to network, communicate with each other and their colleagues, set up local affinity groups, and receive advice and support from others as well as benefit from the expertise concentrated at the institute and through its publications (in many languages) and web site. This also will empower affiliated organizations to lobby for needed new and revised laws and government issued rules and regulations affecting those with needs related to autism. Further, it will enable such governments to more accurately estimate the demands and costs for their services and thus better meet the needs of these constituents. [Given these considerations, the world's many governments could be another source of revenue for the institute. They could pay fees on a sliding scale (based on population) to access aggregate survey data that would enable them to operate more cost-effectively.]

The institute will provide medical evaluations/diagnoses and treatment plans as well as individualized patient care. It will be a major center for the training of doctors and nurses specializing in such care around the world. It will maintain a multi-lingual web site, enable webinars or on-line seminars, produce documentary/educational films and videos, and publish newsletters, curriculum guides, manuals, and specialized materials for educators, for those trained to serve the autistic community, and for the families of those with the diagnosis of autism spectrum disorder. It will offer training and conduct specialized workshops for social workers, teachers, librarians, electronic and print journalists, emergency first responders (fire, police, ambulance, and emergency room personnel), bus drivers, flight attendants, policy-makers such as legislators, administrators of government departments, attorneys, and the parents or other caregivers of children and others who are members of the world's autism "family." The institute will include a conference center with appropriate auditoriums, lecture halls, classrooms, meeting rooms, a gymnasium and swimming pool (for therapy and recreation), a non-denominational chapel for meditation, prayer, and religious/spiritual services or events, and eating facilities. Housing will be provided for those in residence. A day-care facility with a professional staff will be made available for the autistic so that the rest of a family can attend workshops or training opportunities or be assisted while patients are receiving medical evaluation and care over an extended stay. Group living quarters will be established for the use of part of the autistic population as well as a long term care facility for the elderly.

The institute will host a series of world-wide conferences that periodically will bring together leading thinkers to focus on all aspects of autism. The meetings, talks, and discussions (which will be broadcast) will emulate some of the features of the TED (Technology, Entertainment, Design) Conferences: a set of annual gatherings run by the private non-profit Sapling Foundation and offering live streaming of talks. [They offer free online viewing under an "Attribution-NonCommercial-NoDerivs Creative Commons" license through TED.com. In-person attendance is included in an annual membership fee of \$6,000.00 that also covers mailings and the cost of conference DVDs. TED is funded by fees, corporate sponsorships (by Google, GE, AOL, Goldman Sachs, and The Coca-Cola Company), foundation support, licensing fees, and book sales. See: [https://en.wikipedia.org/wiki/TED_\(conference\)](https://en.wikipedia.org/wiki/TED_(conference)). For a collection of TED talks (and their

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transcripts) on the topic of autism spectrum disorder, see: <http://www.ted.com/topics/autism+spectrum+disorder.>]

Similarly, The Edge Foundation, Inc. is an association of science and technology intellectuals created in 1988 by John Brockman. Although direct participation is by invitation only, the discussions of intellectual, philosophic, artistic, and literary subjects are broadcast and freely available (including transcripts). The Edge motto is: “To arrive at the edge of the world’s knowledge, seek out the most complex and sophisticated minds, put them in a room together, and have them ask each other the questions they are asking themselves.” [For a link to all the conversations (which include video and transcripts), see: <http://edge.org/conversations>. For a good overview of the scope and nature of the presentations and discussions, see the following works, all edited by John Brockman: What to Think About Machines That Think: Today’s Leading Thinkers on the Age of Machine Intelligence (New York, N.Y.: Harper Perennial, 2015), This Idea Must Die: Scientific Theories That Are Blocking Progress (New York, N.Y.: Harper Perennial, 2015), What Should We Be Worried About?: Real Scenarios That Keep Scientists Up at Night (New York, N.Y.: Harper Perennial, 2014), Thinking: The New Science of Decision-Making, Problem-Solving, and Prediction (New York, N.Y.: Harper Perennial, 2013), Is the Internet Changing the Way You Think?: The Net’s Impact on Our Minds and Future (New York, N.Y.: Harper Perennial, 2011), This Will Change Everything: Ideas That Will Shape the Future (New York, N.Y.: Harper Perennial, 2010), What Have You Changed Your Mind About?: Today’s Leading Minds Rethink Everything (New York, N.Y.: Harper Perennials, 2009), Science at the Edge: Conversations with the Leading Scientific Thinkers of Today (New York, N.Y.: Sterling Publishing Co., Inc., 2008), What Are You Optimistic About?: Today’s Leading Thinkers on Why Things are Good and Getting Better (New York, N.Y.: Harper Perennial, 2007), What Is Your Dangerous Idea?: Today’s Leading Thinkers on the Unthinkable (New York, N.Y.: Harper Perennial, 2007), and What We Believe but Cannot Prove: Today’s Leading Thinkers on Science in the Age of Certainty (New York, N.Y.: Harper Perennial, 2006).]

This think tank could be a not-for-profit (as opposed to a non-profit) organization like the Rand Corporation in California or the Illinois Institute of Technology Research Institute in Chicago and thus be able to charge fees.

PART 6: A PROPOSED COMPREHENSIVE MEDICAL SCHOOL TEXTBOOK ON THE AUTISTIC BRAIN AND ITS EVALUATION AND TREATMENT.

In the near future we will describe in some detail how we will procure funding for and collaborate with a group of specified world experts to design, research, write, publish (and keep up-to-date with periodic revisions), and distribute a definitive, comprehensive medical school textbook on the autistic brain and its evaluation and treatment (including computerized images and an instructional DVD). This will be sufficiently funded so that copies will be distributed to all major hospitals in the United States and to medical libraries around the world. [See: Z. Josh Huang and Liqun Luo, “It takes the world to understand the brain: International brain projects discuss how to coordinate efforts,” Science, Vol. 350, No. 6256, October 2, 2015, pp. 42-44 and Andrew Schwartz, “Editorial: The promise of neurotechnology,” Science, Vol. 350, No. 6256, October 2, 2015, p. 11. See also a special Supplement to the same issue of Science: Advances in Computational Psychophysiology, especially Su Lui, Du Lei, Weihong Kwang, et al., “Magnetic resonance imaging of mental

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disorders: A multimodal approach for psychoradiology,” pp. 7 and 8 and Choong-Wan Woo and Tor D. Wager, “The predictive mapping approach to neuroimaging,” pp. 18-21.]

PART 7: A PLAN FOR MASS MEDIA EDUCATION ABOUT AUTISM.

We plan to obtain sufficient funding to revise and complete a script for a major film about autism and procure the services of a successful director, producer and leading actors associated with a major studio in order to create an opportunity to educate the mass public around the world. A regular television situation comedy or autism family portrayal could also be produced. We hope that by increasing the public’s exposure to information about autism that people will not only become more familiar with the subject but that they will become accustomed to dealing with it on a day-to-day basis as they encounter it. Thus, their view or attitude and opinion (which we will document with survey data) about autism will change so that eventually society as a whole will embody a more compassionate understanding that will be expressed as a collective willingness to devote more resources to the issues and needs surrounding it. [In order to bring dramatic attention to the subject of this film effort, we have had preliminary discussions with the staff of the Dalai Lama in Dharamsala, India about the possibility of having His Holiness appear in a brief scene showing him having an audience with a group of folks on the autism spectrum (including an actress in the film who is autistic). The Dalai Lama has shown considerable interest in behavioral and biological brain imaging research focusing on meditation, including its efficacy for those having autism. He has visited the Waisman Center at the University of Wisconsin-Madison which includes the Intellectual and Developmental Disabilities Research Center, one of almost seventy such programs in the United States. This renowned institution would be a logical candidate to join the consortium proposed above. (See on-line: <http://www.waisman.wisc.edu/IDDRC.htm>.) The pioneering neuroscientist Richard J. Davidson, founder and leader of these efforts in Wisconsin, has written extensively about treating autism and depression and our “emotional fingerprint.” See: Richard J. Davidson with Sharon Begley, The Emotional Life of Your Brain: How It’s Unique Patterns Affect the Way You Think, Feel, and Live -- and How You Can Change Them (London: Plume, Penguin Books Ltd., 2013), especially pp. 140-148.]

PART 8: FUNDING AND BUDGET CONSIDERATIONS.

We presently are developing a separate, detailed and comprehensive funding proposal and budget for philanthropists, foundations, universities, and/or other supporters of these efforts. We estimate that the cost for implementing all these ideas would total about \$2 billion. Another possibility is the creation of a 501(c)3 non-profit foundation devoted to funding some or all of the activities and projects described here.

BIOGRAPHICAL NOTE

Mr. Appel has a B.A. in Political Science from New York University, an M.A. in Political Science from The University of Michigan, and has completed all the requirements for a Ph.D. in Political Science except a dissertation at The University of Michigan. He has taught undergraduate and graduate students at The University of Michigan, The Illinois Institute of Technology, DePaul University, and Loyola University Chicago. For nine years he served as Principal Operations Research Analyst for the City of Chicago. He is President of John S. Appel and Associates, Inc., providing research, data analysis, and policy advice for government, corporate, and private clients. He is also a microscopist and has worked as a

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professional photographer for the Associated Press. For ten years he was president of an NGO (Non-government–organization), VEZA, International, an economic development organization, directing projects in Malawi, Africa.

[See: <http://peacecorpsonline.org/messages/messages/467/1011500.html>.]

Ms. Forest has a grown daughter with autism who has been on boards, lobbied Washington DC, written 2 recovery workbooks for children displaced by disasters, a career in acting, and plans to stay in society. Nina is a graduate from Baylor University, and got her masters in international economic development with a magnum cum laude from West Virginia University with projects in Washington DC. She has a medical textbook set which maps the autism brain with educational DVD. In her former career, she did hospital regulations and brain research. Her father did international relief work in Japan and Okinawa, which had coverage by the National Geographic magazine. She is presently placing multi-billion deals with Chinese investors, to gather the money for a feature film and publishing and distributing the medical textbook set.

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