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From Rainman to Rainmaker: A Presentation of Jim's Journey and Rapidly Advancing Technologies: Integrating Proven Behavioral Therapies with Emergent Measurement and Testing Advances Will Result in Transformational Progress in Autistic Individuals

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The autism treatment status quo was reviewed and accompanied by a narrative contextualizing past and present progress with my younger brother Jim's journey with the condition, sharing proposed next steps for bettering the current state of affairs in the space. The impetus for this piece was to share in the lessons of Jim's life thus far and the revelations of those who have supported him, as well as to determine ways to create more impactful, lasting change in the limited window of early intervention therapy whilst empowering individuals on the spectrum to optimize for their skills and talents rather than just simply mitigating the downsides of autism spectrum disorder. Feedback as to how to improve the prevailing course of treatment: (education and therapy) was solicited by leading experts in the fields of Applied Behavior Analysis (ABA), Electroencephalography (EEG), and autism more generally in the context of politics, insurability, and savant syndrome and splinter skills. The advice of the various vertical experts were synthesized and distilled into a new proposed course of treatment which were submitted to all respective experts for further feedback and review prior to publication. It was discovered that there is significant feedback to suggest that the prevailing wisdom that splinter skills and savant syndrome are found in a small minority of individuals with autism spectrum disorder may not be true and that further research is warranted that would implement the new proposed course of treatment and attempt to unlock the talents and gifts of these individuals consistent with the success we encountered raising Jim. While our methods were resource-intensive and conducted manually with many hours of intensive in-home therapy, there is significant feedback to suggest that a technology-driven approach to reforming autism treatment would achieve same or greater results with far fewer resources in the near and long term. By unlocking the greatest minds of our society (the majority of savants have historically been autistic) to take on the greatest challenges of our time, we can rapidly accelerate the progress of humanity and exponentially better the trajectory of society's future at the global scale.

Autism Spectrum Disorder is defined by a marked deficit in social behaviors, specifically communication and interactions, as well as by repetitive patterns of behaviors or interests. Symptoms typically develop early in life and cause significant impairment across many areas of functioning, including social and occupational functioning (Diagnostic and Statistical Manual of Mental Disorders V). While the Diagnostic and Statistical Manual of Mental Disorders provides a definition for autism spectrum disorder, it is important to note that autism is highly individualized, presenting unique symptoms in each autistic individual in different phases of life. Further, no test currently exists that provides a definitive diagnosis of autism. Diagnosticians or teams of specialists who may be involved when the child first presents symptoms are often diverse and disintegrated and can include primary paediatricians, developmental paediatricians, child psychologists, paediatric neurologists, and special education teachers. Diagnosis is typically based on observations of the individual's behaviors, traits, and activities. Given the vast number of ways autism can present itself, the large number of symptoms, the lack of diagnostic testing, and the lack of a specific diagnostician, it is unqiue that autism is typically treated in one manner: applied behavioral analyis therapy.

Currently, the most effective therapy for responsive children and adults on the autism spectrum has been based on applied behavior analysis (ABA) research (Foxx 821) and implemented through conditioning that reinforces *desirable* behaviors and skills, while extinguishing *atypical* behaviors. This approach began with research from Lovvas (3) and enhancements from researchers and clinicians, which include, but are not limited to: "errorless training" (Ducharme and Drain 163), elimination of the use of aversive methods, and many subsets, such as intensive 40-hour-per-week in-home therapy and center-based programs. Traditional behavioral therapy (Rao, Beidel, and Murray 356) focuses on didactic techniques to

reinforce baseline skills while extinguishing atypical actions. While initially effective in teaching autisitic individuals situation specific skills, this form of therapy is less impactful than approaches integrating emotional and executive intelligence through linking splinter skills with episodic memories and "planned failure exercises" (Greenspan 2). Traditional ABA therapies have been remarkably effective in improving baseline skills and developing speech, motor development, eye-contact and academic achievement, but they have generally been unsuccessful in creating the executive and emotional intelligence required to learn independently, and to think and reason using emotional and executive parts of the brain. In fact, in some cases, the behavioral therapy efforts to extinguish unusual or atypical behaviors have also resulted in suppression of splinter skills (De Myer et al. 240; Happé and Vital 1369), which are a critical component in linking higher brain function with emotional and executive development (Snyder 1400).

The wisdom of the proverb "give a man a fish and feed him for a day; teach a man to fish and feed him for a lifetime" may seem supportive of traditional behavioral teaching therapies as a matter of first impression. A paradox here is partly in the lexicon where behavioral therapy is considered to be *teaching* skills (Beck 112). This observation holds in the sense that teaching an autistic child to button a shirt through behavioral therapy versus giving him the already buttoned shirt conforms to the premise of teaching *for a lifetime*. If we accept the premise that autism spectrum disorders represent a complex set of developmental delays centered around a profound lack of emotional and social connection and a dysfunction in the executive part of the brain (Hill 189) required to integrate prior learning to make good decisions − and to learn without teaching − it follows that traditional therapies we have are addressing the symptom rather than the underlying problem. In essence, simply teaching skills and suppressing certain behaviors does

not challenge nor, therefore, enhance missing executive and emotional processing. Simply teaching skills to autistic persons is more like "giving a man a fish" because the *teaching* is providing skills rather than promoting and challenging the executive and emotional responses required for addressing profound underlying deficits in emotion, judgment, and independent acquisition of skills.

For example, teaching an autistic person that if a light bulb goes dark then it needs to be replaced, and then showing them exactly how to replace the bulb in a didactic manner, does not trigger the synaptic energy required to integrate the executive and emotional components of the brain to solve problems and develop an episodic memory that is positive and therefore reinforces emotion judgment (Gutstein and Sheely 278) and independent acquisition of skills. The alternative to this is mentoring an autistic person to observe or *co-observe* a burned-out light bulb and be gently prompted through non-verbal cues to ignite the power of the executive side of the brain (Baron-Cohen and Swettenham 881) to a point where the autistic person is leading the charge to solve the problem, with the parent or mentor acting only as a coach or role model where needed. In this case, we are not just *teaching* in-person how to change a light bulb, but we are rather activating the portions of the brain required to identify and solve problems while experiencing the remarkable episodic memory associated with this type of success and achievement. Episodic memories (Goh and Peterson 210) are powerful anchors that we all have from our life experiences and can be as simple as the joy of a family vacation, or as complex as the sense of satisfaction a typical person experiences when identifying and solving a problem through the integration of acquired knowledge and intelligence.

While on one front ABA therapy is lacking due to its focus on situation-specific skills over improvements in brain connectivity and synapse energy, it is also inefficient. In order to be

successful, ABA therapy requires large time commitments, often over 40 hours per week of intensive therapy. This isn't a privilege afforded to most autistic individuals. This is partially due to the lack of certified practitioners offering this intensive amount of therapy, but also problematic in that therapy costs large amounts of money, preventing many families and individuals from being able to afford it. Further, in cases of families with an autistic child and a household in which both parents work, many families are simply unable to get their child to therapy this often. The problems with ABA therapy are inherently cyclical. ABA therapy requires such large time commitments because of its focus on situation specific skills, which may not be the most effective strategy to produce generalizable and long-term improvements in autistic individuals. As more research becomes available on autism and technology advances in ways that may be relevent to the treatment of autistic behaviors, it becomes necessary to develop ABA therapy along with these changes.

For my younger brother Jim, early intervention was critical and impactful. Receiving the full forty hours of ABA suggested for optimum therapy was a rare feat in the early 2000s when many U.S. families were still struggling to get any care or therapy at all. Anna Laakman, the Director of Education and Training at the U.C. Irvine Center for Autism & Neurodevelopmental Disorders, stated during the interviews for the film portion of this thesis that families in Southern California receive on average only six hours of therapy per week, and are often subject to copays from insurance companies that often make ABA therapy cost-prohibitive. Our family had to employ trial and error with many hours of intensive therapy, using what computer science might call a "brute force" approach to gaining access to the often seemingly cryptic brain of the autistic child.

A gap exists between recent research and technological improvements and the ABA strategies currently being implemented with autistic individuals. ABA therapy can be optimized utilizing this new technology and what we have learned about autism through recent research in a vast number of ways. Rather than a brute force attacking the problem, a strategy utilized by many ABA therapies currently, we must narrow our approach to only what works based on research and we must utilize the technologies now available to us that were not existent when ABA therapy first emerged.

For example, a recent study by Barnea-Gorlay, Kwon, Menon, Eliz, Lotzspeich, and Reiss (2004) studied white matter structure in young individuals with autism in order to verify previous suggestions that abnormal connections between brain regions relevant in social behavior may be contributing to the social limitations in autistic individuals (Barnea-Goraly, Kwon, Menon, Eliz, Lotzspeich, and Reiss 325). The researchers' results demonstrated that disruptions in white matter did in fact exist in young autistic individuals' brains specific to areas of the brain involved in social functioning. The researchers concluded that this disruption may contribute to the social defecits experienced by individuals with autism. This information reinforces the idea that ABA therapy needs to focus on triggering the synaptic energy required to improve brain functioning rather than focus on a simple acquisition of skills in order to produce long-term results that can be replicated independent of therapy sessions and across multitudes of situations.

By increasing synaptic energy and strengthening connections between the executive and emotional components of the brain, autistic individuals will learn not only the skills to respond to a specific situation, such as changing a light bulb when it burns out, but will be able to better generalize the skills acquired in a specific instance across many similar situations, perhaps to

changing the batteries in the television remote when they die as well. Further, by approaching ABA therpay in this way, therapy becomes more individualized than before. As each brain is unique, each autistic individual will require different strategies, situations, and triggers in order to increase synaptic energy and activate the parts of the brain required to identify and solve problems or to increase social behaviors. Individualizing therapy also has the benefit of being more likely to increase episodic memory, as the strategies used will be relevant specifically to the individual's interest and engagement.

Robins and Dautenhahn's (2014) research is at the crux of this combination. Utilizing research-verified techniques and technological advances through robots, the researchers were able to improve the social behaviors of autistic individuals. In the experiement, autistic children were taught to play with a robot utilizing excerises based on Mihaly Scikszentmihalyi's concept of flow, described as "the mental state that a person had during an acitvity characterized by the energy and joy that motivate the person to perform the activity… [or] the pleasing or fun moment of an action where the challenge of a new activity combines with the personal skills of each individual" (Robins and Dautenhahn 403). Play has been proven to improve social and language development as well as cognition, hence its importance for autistic children. The robots proved useful in engaging the autistic children as well as promoting spontaneity in play, something that is uncommon for autistic individuals. The researchers found that the scenarios of the experiment "promoted the children to take initiative in their interaction, help the emrgence of awareness of cause and effect and help to link 'sad' expression to being 'hurt'" as well as helped "some children to extend their focus and concentrate skills whist at the same time further developping a sense of self" (Robins and Dautenhahn 410). This research is an ideal example of the ways that ABA therapy can be improved upon through the use of modern research.

Technological advancements, such as the availability of EEG tests, also may be relevant in improving ABA therapy when used in concert with one another. EEG tests record the electrical activity of the brain and would provide valuable insight into areas of the individual's brain, specifically which connections need to be strengthened the most, and therefore which areas of improvement should be focused on by therapists. By utilizing EEG tests while implementing ABA therapy with autistic individuals, therapists and doctors will be able to better track brain activity and detect abnormalities, as well as see what strategies are most effective in increasing synapse firing and connectivity across executive and emotional brain structures. When implementing ABA therapy in concert with EEG tests, therapists will know if the strategies being implemented are increasing brain function where it may be lacking or not, and thereby adjust their strategies if the current strategy is not effective. This improves the individualistic focus of ABA therapy and the attention paid to each autistic individual's unique differences in brain functioning and brain connectivity. Even more simply, EEG tests will be able to show when an autistic individual is focused or not, increasing therapists' ability to use time effectively, reducing the need for intensive 40-hours-per-week therapy.

EEG is the only widely available brain scanning technology that is currently capable of sub-second refresh rates. It is also manufactured at a cost accessible to autism treatment centers and schools public and private; it is ideally situated for deployment in real-time in ABA treatment centers. By pairing Independent Component Analysis to extricate meaningful signals from the noise of the brain by using the Confusion Matrix, it is possible to understand if a child is concentrating under the same premises as the FDA approved use case of EEG Neurofeedback: measuring focus in ADHD. Utilizing EEG with ABA therapy is just one of many examples of technological advancements not currently being utilized to maximize efficiency, time, and

success with autistic individuals, but one that has a large number of applications and the ability to focus and improve therapeutic techniques.

I hypothezise, and preliminary dialogues with specialists in ABA, EEG, and Machine Learning corroborate this, that it will be possible to determine whether flow is present in the brain of an autistic individual with a degree of confidence that far outpaces that of current behavioral estimations of ABA therapists. From a clinician's standpoint, such a "dashboard" would be invaluable as a toolkit to be used in the ABA therapy process' an ambiguously stoic face of a child being treated with autism could quickly blossom into a cornucopia of data providing insights into which of the myriad activities presented during the ABA therapy process are effective, and which are not eliciting a response. Further, determining which activities produce cognitive flow would allow an early inventory of potential splinter skills and giftedness (if not savant-like traits) in children with ASD receiving EEG-empowered ABA therapy. Using these algorithms to elicit meaningful feedback from the brain is part of a larger field of academic and scientific exploration known as "brain-computer interfaces". The increasing prevalence of Apple iPads and technology more broadly during therapy mean that actionable outputs can be provided from these highly technical readouts through today's currently available technology. A scale ranging from "no focus" to "complete flow" could be provided in a more advanced version to allow the clinician to quickly and effectively tailor ABA activities and goals to empower the strengths and mitigate the present pitfalls of the autistic individual's skill set. This would be aligned with the interests of insurance companies, as from an actuarial standpoint they are motivated to mitigate risk against million-dollar-plus costs associated with long-term care of a "mentally disabled" autistic individual who is unable to achieve independence due to the lack of early ABA intervention, costing only tens of thousands of dollars in comparison.

ABA therapy has not had the chance to catch up to these research and technological advancements. ABA therapy has laid a groundwork that has the potential to be optimized to identify the best channels to reach a patient, utilize time most effectively, and produce the greatest long-term improvement in social, emotional, and cognitive funcitoning. When ABA therapy is paired with technological advances in robotics, medical devices, and medical imaging the opportunities for improvement in therapeutic techniques and strategies are limitless. The future holds remarkable promise as the fields of traditional autism treatment, genomics, neuroscience, and personalized medicine converge to offer unparalleled advances in the field to individuals on the autism spectrum and their families. Traditional ABA therapy sees therapists spend the majority of the day graphing using paper and pencil and only a small portion of their day actually working with children. Incremental advancements such as Delian Asparouhov's Nightingale in the way therapy is approached have come out of Silicon Valley: digitizing the traditionally handwritten therapy logging progress and providing valuable insights. While meaningful and impactful to families, that the digitization of the ABA therapy process represents an award-winning advancement in the autism field as recently as 2015 underscores the antiquation of the vertical within the context of the broader medical field and the need for exponential disruption.

It is my recommendation that a clinical trial be developed to vet and employ this suite of technology to empower the brightest minds of our generations to take on their passions and dreams and achieve peak potential over the course of their lifetimes. As many of the brightest minds of our time have been supposed or confirmed to have high functioning autism, it would be doing a disservice to humanity if we did not work swiftly and passionately to support our most brilliant minds toward a life of passionate purpose.

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