Written Public Comments

IACC Full Committee Meeting

December 11, 2009

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Daniel Pech

November 11, 2009

Subject: SIGNS: Autism Undercover

[PII redacted]

"Tell Graham...tell him.......see." -------SIGNS, starring Mel Gibson and Joaquin Phoenix

Author's ABSTRACT
In a society dominated by normal persons, it can be expected that abnormal or otherwise disadvantaged persons will have the greatest difficulties---especially if their disadvantages are misunderstood or unrecognized. But, the appearance of doing well in life does not prevent even 'normal' persons from experiencing mid-life crises, burnout, confusion, and even addictive, repetitive, or reclusive patterns of coping. Autism is a behavior driven by a disability, and both the behavior and the disability occur in the normal population.

Imagine you have debilitating stage fright. You go up on stage to speak, and your throat tightens. You can't think, and your mind freezes in fear. Suddenly, you can't bear it anymore, and you walk off-stage and into a back room. The cumulative expectation of the crowd was palpable---at least to you--so it overwhelmed your congruent sensibilities (speech and thought) while leaving your other sensibilities relatively intact (including vision, decision-making, and bipedal locomotion). Somehow this debility occurred even though you are your own person. It should be expected that, as your own person, you should be able to function independently of your sense of the expectations or feelings which others have of you. But, this was not the case here. Why?

Some people will answer that the reason you were unable to function linguistically and mentally while on stage was because your fight-or-flight response was so fully activated. That is, your fear of the crowd so overwhelmed your 'finer' abilities (such as speech and thought) that you became unable to function as the anticipated speaker but were still able to flee the stage. But, this does not actually answer the question. The fight-or-flight response is a symptom, not a cause. And, in your debilitating stage fright, it was being activated by something. The question is, BY WHAT?

As a social creature, you are capable of being emotionally effected by the expressed feelings of other persons. This includes both overt and subtle expressions, and involves the whole range of emotions: anger, joy, etc.. It also involves whether or not these emotions are directed at you in terms of what those persons think of you ("He's so lame", or "Yeah, he's so right, the cop was clearly being a [offensive language redacted]"). But, if this is so, then it can be expected that formal social gatherings, by their formal nature, would have a dimension of power that informal gatherings have not. In fact, formal gatherings do have this power, and it is a function of the cumulative effect of each person upon a given one of them. Virtually each individual in that gathering infers, or imputes, that collective power into the expressions of all those involved. This is why, for example, a large audience is more dynamic than a small audience, especially if the members of the small one are disappointed for having expected a large one.

But, your stage fright (or your radio talk-show fright) is caused by your sincerely inferred imagination of the cumulative expectation of the more-or-less formal audience. This is so even if you cannot see or hear the audience---or even if, unknown to you, there actually is no audience. In the case of your debilitating stage fright, your independent social faculties were so outweighed by your imagination of the crowd's cumulative expectation that you were unable to ignore it sufficiently so as to function as your own person.

All this may seem odd to those who, despite having themselves been on stage, have never suffered stage fright. But, the far more odd thing would be if no one in that crowd of yours had ever heard of, or even experienced, stage fright. In that case, they would have found your behavior incomprehensible: you utterly failed to behave socially as they had hoped, and they cannot see why you behaved the way you did. But, regardless of what the crowd thinks, your behavior was---by definition---autistic. That's what I said: autistic. It may have been temporarily so, but it was definitely so.

Your behavior from your debilitating stage fright was temporary only because the context in combination with which your debility arose was temporary. Moreover, the temporality of that context was special and formal, unlike normal human social activity. Your behavior was definitely autistic within the positive social expectations of that context. Thus, autism is to be understood as being defined by the context, whether or not that context is enduring.

But, autism is not necessarily the developmental form which you may have assumed I meant. Autism proper is the general category, while 'temporary' and 'enduring' are the two immediate sub-categories of autism. The latter sub-category, 'enduring', includes---but is not limited to---developmental autism.

The study of developmental autism is still in its infancy (and, unless otherwise specified, I shall henceforth refer to it simply as 'autism'). Most people, including most specialists, still commonly hold the notion that the usual behavioral signs of autism more-or-less are the disability. Considered to be the key signs of the disability are social difficulties, language delays, and narrow interests. But, developmental autism is not, at root, about social difficulties, language delays, or narrow interests. In fact, most specialists now almost admit as much: they recognize the heterogeniety of the hundred's-of- thousands of cases of which they are aware, and that these cases, taken together, encompass a very wide range of characteristics---so wide, in fact, as to belay the nature of those who suffer the disorder: fully human.

In 'the earlier days' of autism research (twenty and more years ago), so few children suspected by their caretakers to have an unusual mental, social, auditory, or linguistic disability had yet been brought in to be diagnosed. Consequently, the definition of autism as a disability was rather more narrow and superficial than it is today.

Today, there are many insightful ideas as to the exact neuropsychological nature of autism. Perhaps the three most prominent of these are the 'Extreme Male Brain' theory of Simon Baron-Cohen, the 'Intense-World Theory' of Henry Markram, and the 'Empathy Imbalance Hypothesis' of Adam James Smith. Being perhaps the first idea to shake the field of autism research, Baron-Cohen's idea is that autism is somehow a function of the cognitive propensities characteristic of human males, specifically the tendencies of systemizing and narrow focus. Baron-Cohen recognized that the behaviors and abilities in autism were partly characterized by these same male tendencies, and that it did not seem to involve the holistic thinking, and emotional empathy, of human females. It is thought by many that an extreme systemizing ability, along with an extreme ability of narrow focus, explains the savant abilities often present in autism. Baron-Cohen also pioneered in research that confirmed that autistic person's lacked an adequate sense of the fact that other persons have minds which are functionally independent of their own and thus which are capable of having points of view which the autistic person does not directly have (called the 'Theory of Mind', or ToM, problem). Markram's idea is that autism may at least partly be a function of an intensely aversive perception of the world, involving a hyper-active amygdala (the brain's management-center for emotion and for general sensory input). Markram's ground- breaking---if decidedly un-Kosher---neurological research suggested that persons with autism must experience various normal stimuli far too intensely and thus are forced to withdraw from the stimuli. Smith's idea is that autism may, ironically, be caused by the exact opposite of what normal person's initially imagine from the social behavior for which the term 'autistic' was coined: normal persons initially get the impression that autistic persons, by their markedly non-social tendencies, must lack the emotional empathy which drives normal, pro-social behavior. Smith's research, in keeping with Markram's 'Intense-World Theory', has shown that, in fact, this impression is very often exactly the reverse of what is actually experienced by many autistic persons. Smith has further shown that, in keeping both with Baron-Cohen's 'Theory of Mind' research and Markram's own theory, autism often involves an empathic imbalance: over-arousal of direct emotional empathy (such as seen on other's faces or body language, or heard in other's voices), and a poor ability to infer other's invisible mental states [in real-time].

But, according to...me, autism is not about hyper-sensitivities, savant abilities, or empathic imbalance. It is not even about intensely aversive perception of the world (or of the limited context, such as the stage). While all these things are often involved in autism, not one of them is even part of the root problem. This is because autism is not the problem. Autism is not a disability. Autism is a behavior.

The human organism, in order to survive, must make, and maintain, a perception of the distinction between itself and its environment. This is because it must be able to identify, monitor, and act effectively in the interests of, itself as distinct from its perceptions of the forces of its environment. (All environments are essentially dynamic, involving change, progression, and cycles. But, up to a point, it is the level of integrity at which an organism can easily-and-automatically maintain itself which constitutes the distinction between what is, for it, static, versus dynamic, forces). This ability to maintain integrity within the dynamic pressures of environment is what may be called 'dynamic autonomy'. What you experienced in your debilitating stage fright was an overwhelmed dynamic autonomy----specifically, the personal-cognitive/social facet of that autonomy.

Autism is a basic mechanism of the organism's function of self-preservation, both as a behavioral result of, and as a basic coping mechanism against, the environmental pressures which cause an anti-integrity imbalance between self and other, between ability and environment. Many cases of PTSD (Post- Traumatic Stress Disorder) in developmentally normal persons involve this mechanism. Developmental autism is defined as the activation of this mechanism by way of a chronic enfeebling of the immature person's dynamic autonomy, so that the person finds various parts of the normal dynamic environment overwhelming to his or her functional integrity, forcing him or her to withdraw into sub-par, non-normal functioning for such a cumulative duration that he or she fails to develop normally within that time- frame. Autism is thus not a disability, but a behavior driven by a disability: an enfeebled or otherwise overwhelmed, dynamic autonomy.

Most interestingly, the disability of an enfeebled dynamic autonomy does not necessarily result in autism (good bye, Norma Jean, Heath Ledger, etc.). There has been a widely held belief that, as a rule, persons with autism spectrum disorders have an excess of personal autonomy. One part of the reason for this belief is that the outstanding behavior marking these disorders is a general indifference to the social world.

Another part is the very term itself: 'autism'. It suggests that persons given the label of 'autistic' are immediately and exclusively self-absorbed, and must be taught to relate to others.

The term 'autism' was coined to describe the characteristic non-social behaviors of certain persons. But, at that time, little was known of the underlying cause of these behaviors. Why did these persons prefer to act alone in their own little worlds? Why did they wish to avoid interacting with others? Consequently, the term came to be used to denote an actual disability---or, at least, the notion of one. The notion was that these persons had a poor over-all sense of others, especially of what others felt. After all, human social behavior is driven by emotions of relatedness to others: of wanting to relate to others, and of wanting to be related to. So, the label of 'autistic' helped solidify the impression that these persons lacked the general, 'other'-oriented empathy which is most naturally assumed to be the singular key to normal social ability.

But, perhaps the most critical reason for the belief that persons with autism spectrum disorders have an excess of personal autonomy is because they do, in fact, seem to lack the instinctive social ability which normal persons take for granted. In fact, it has been demonstrated, countless times, and in all kinds of settings, that these persons are unable readily to negotiate the social world. Such an inability suggests a lack of a basic knowledge of the common-sense rules of human interaction. Consequently, much effort has been spent developing techniques to teach persons with autism spectrum disorders how to interact with others, including techniques that involve explicit instruction in these common-sense social rules. But, without knowing what actually drives autistic behavior, it is impossible to ascertain whether these techniques are not actually counter-productive to their own ideal ends. When persons thought to need to be taught more-or-less like computers are actually overwhelmed by their concern for what others wish of them, the teaching becomes a self-fulfilling prophecy.

I, for example, often fail to possess a sense of my own current learning-actions upon some machine while being expected by someone to follow their active instructions on how to operate the machine. Also, my entire mind and psyche is often so at the mercy of anyone who, while in conversation with me, expresses opinions or feelings that are not my own: it's like getting hit in the chest by a huge truck every two seconds, my whole sense of reality is being hijacked, including my sense of myself, my identity, my duties and rights, and my place in that reality. It is often very unpleasant, to say the least, especially when the person has ideas about me that are uncharitable and mistaken. And, the basic problem is magnified by the fact that my socio-linguistic, and cognitive-empathy, response is often exactly what the person expects per their misconceptions of me. I am never given the 'middle-ground of approach'. This middle-ground of approach is analogous to what a band of 'Indians in the movies does when: when a band of 'Indians' and a band of white men attain a mutual recognition from a distance, the band of 'Indians' will approach to a point halfway to the other band and stop, allowing the other the option to engage, or not engage, in diplomacy. Writing by myself with no vicarious or other pressure from another human being, is my only means of a middle-ground.

In keeping with Smith, Markram, and others, it is conceivable that autistic behavior in persons with developmental autism is driven not by an excess or personal autonomy, but by a severe lack of it.

According to Donna Williams' account of her autism (in her four books, beginning with 'No One, Nowhere'), the underlying disability causing 'autism' (autistic behavior) appears to be an inability fully to process dynamic sensory and, or social, stimuli concurrently with how this stimuli dynamically effects the self. In normal development, the self is more-or-less dynamically equal to the dynamic stressors of environment, allowing the person to adapt, grow, and mature. But, in the disability causing autism, everyday dynamic stressors are, in effect, overwhelming to dynamic personal autonomy, preventing the person from sufficiently adapting.

Autism thus appears to stem from something analogous to the 'jelly legs' which a young woman might experience in her first dance with her 'dream boy': she may be so overwhelmed by his special presence-and-attention that she has too little brain-power left to manage her own part in the dance. She may stumble, or even fall; and she may become so embarrassed or frightened by her poor performance that she suddenly bursts into tears and runs off to hide in the bathroom. The problem she is having is what I call an overwhelmed dynamic autonomy: she is effectively so disabled by her emotions toward the boy that she is unable continuously to re-adapt to the demands of the dance.

Autistic persons are noted to have difficulty perceiving a distinction between themselves and their environment. But, this difficulty is not unique to autistic persons. In fact, virtually all normal persons have a certain difficulty perceiving a distinction between themselves and their environment---though often not in the same ways as have autistic persons.

Interestingly, many a thing about which normal persons have difficulty perceiving a distinction between themselves and it are things about which autistic persons often have little or no such difficulty. Consider the fact that normal persons commonly fail to distinguish between their visual perception of the world and the actual state of the world. Normal persons commonly start out by assuming that their visual perception does not merely represent the world but is part of what the world actually is. Contrary to your end-state subjective visual experience of the world, your visual perception is not immediate or direct, nor is it the result of a simple process.

The world does not, in itself, have an image or appearance, any more than, say, an apple has a taste, or than the electronic speaker system in a conference hall has an understanding of the spokesman's words which it is reproducing. There is no image in the world; there is no taste going on in the apple; and there is no sentient mind in the electronic speaker system. Does a British accent have a native Chinese ear, an American ear, or the 'plain, flat, accent-less' ear of a British person? Does a hot stove burn itself and feel pain? Does a cool summer breeze relieve its hot, sweaty body? Does a joke find humor in itself so that it would laugh if only it had a mouth?

Your eyes are not windows from out of which you see the world; they are specialized organs for transmitting light to your optic nerve which, in turn, reacts by sending impulses to your brain. These impulses are in the 'language' which your brain understands: electricity. Your brain processes the electrical information of the optic nerve---and in a very complex way---, the end-result of which is that you have a visual experience.

Important to understanding autism and its cause is the fact that your brain, in 'doing the seeing', is pro-active and aggressive. It does not simply sit back and hope the optic nerve will make the picture. There thus is a balance, or teamwork, between your brain and your optic nerve: your brain acts with a forcefulness that is in some sense equal the forcefulness of the impulses of the optic nerve. If your brain does not act aggressively enough, then your visual experience will be one of a jumbled, or even 'pixilated', picture. Your brain must act not only in concert with your optic nerve, but must in some sense act autonomously from it. Your optic nerve does not see, nor can it make your brain see. Your brain must have the kind of energy needed to make itself...SEE..

But, let's say that your brain were too feeble in its job of processing the information of your optic nerve. In other words, that your brain's visual-processing autonomy is effectively weaker than the electric- impulse autonomy of your optic nerve. In this case, your brain's visual processing would be overwhelmed by your optic nerve, making your visual experience commensurately incoherent, and possibly even causing you a psychic sense of distress or lack of control. Autonomy is another word for functional distinction.

Only a non-random entity can have a concept of randomness. In other words, the mark of intelligence is making important distinctions..

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Carrie Elsass

November 14, 2009

Subject: Responses to the 2009 IACC request for information (RFI) are now Online

Appreciated? So appreciated they were disregarded? What a waste of everyone's time.

Note: Personally Identifiable Information (PII) has been redacted in this document

Daniel Pech

November 16, 2009

Subject: Autism draft in progress, much edited today: title: SIGNS

SIGNS

by Daniel Pech, copyright November 2009 [PII redacted]

"Tell Graham...tell him.......see." ---------SIGNS, starring Mel Gibson and Joaquin Phoenix

Only a non-random entity can have a concept of randomness. In other words, the mark of intelligence is making important distinctions---or seeing the signs. ---------Daniel Pech

ABSTRACT

There is a widely held belief that persons with autism spectrum disorders possess an at least normal level of personal autonomy---a belief based in part on these person's pointedly self-absorbed behavior. Additionally, there is a widely held belief that autism, and its causes, are distinct from various other neuropsychological disorders and their causes, such as schizophrenia, Williams syndrome, and Borderline Personality Disorder. Finally, there is a widely held belief that autism is strictly neurodevelopmental in nature. The present article argues that all three of these beliefs are mistaken. In a society dominated by normal persons, and these dominated by males, it can be expected that abnormal or otherwise disadvantaged persons will have the greatest difficulties---especially if their disadvantages are misunderstood or unrecognized. But, the appearance of doing well in life does not prevent even 'normal' persons from experiencing mid-life crises, burnout, confusion, and even addictive, repetitive, or reclusive patterns of coping. Autism is a behavior driven by a disability, and both the behavior and the disability occur in the normal population. Autism thus is separable both from its cause and from its neurodevelopmental manifestation.

FIRST SIGHTING

Imagine you have debilitating stage fright. Your heart pounds in your ears as you go up on stage to speak to a large, approving audience. You reach the microphone and try to speak, only to find that your throat tightens. Your mind freezes in fear so you can no longer think. You break out in a cold sweat, and the pressure in your face feels as if it is about to explode. Suddenly, you can't bear it anymore, and you stiffly walk off-stage and hide in a back room. Somehow, you have this debility even though you are your own person. It should be expected that, as your own person, you should be able to function independently of your sense of the expectations or feelings which others have of you. But, this was not the case here. The question is, why?

Some people will answer that the reason you were unable to function linguistically and mentally while on stage was because your fight-or-flight response was so fully activated. That is, your fear of speaking to an audience so overwhelmed your 'finer' abilities (such as speech and thought) that you became unable to function as the anticipated speaker, but were still able to flee the stage. But, this does not actually answer the question. The fight-or-flight response is a symptom, not a cause. And, in your stage fright, it was being activated by something. The question is, BY WHAT?

As a social creature, you are capable of being emotionally effected by the expressed feelings of other persons. This includes both overt and subtle expressions, and involves the whole range of emotions: anger, joy, etc.. It also involves whether or not these emotions are directed at you in terms of what those persons think of you ("He's so lame", or "Yeah, he's so right, the cop was clearly being a [offensive language redacted]"). But, if this is so, then it can be expected that formal social gatherings, by their formal nature, would have a dimension of power that informal gatherings have not. In fact, formal gatherings do have this power, and it is a function of the cumulative effect which all those persons have on a given one of them. Virtually each person imputes much, if not most, of that collective power into the expressions of each person there. This is why, for example, a large audience is more dynamic than a small audience, especially if the members of the small one are disappointed for having expected a large one.

Your stage fright (or your radio talk-show fright) is caused by your sincerely inferred imagination of the cummulative expectation of the more-or-less formal audience. This is so even if you cannot see or hear the audience---or, even if, unknown to you, there actually is no audience, since, in the past, you've either experienced or inferred the cummulative power of a crowd. In the case of your debilitating stage fright, your independent social faculties were so outweighed by your imagination of the crowd's cumulative expectation that you were unable to ignore it sufficient to function as your own person. The cumulative expectation of the audience was palpable---at least to you--so it overwhelmed your congruent sensibilities (speech and thought) while leaving your other sensibilities relatively intact (including vision, decision-making, and bipedal locomotion).

Now, all this may seem odd to those who, despite having themselves been on stage, have never really suffered stage fright. But, the far more odd thing would be if no one in that audience of yours had ever heard of, or even experienced, stage fright. In that case, they would have found your behavior incomprehensible: you utterly failed to behave socially as they had hoped, and they cannot see why you behaved the way you did. But, regardless of what the crowd thinks, your behavior was---by definition---autistic. That's what I said: autistic. It may have been temporarily so, but it was definitely so.

EXTINGUISHING FIRST IMPRESSIONS

Most people, including most specialists, still commonly hold the notion that the usual behavioral signs of autism more-or-less ARE the disability. Commonly considered to be the key behavioral signs of the disability are difficulties relating to others, language delays, and narrow interests. But, the disability of autism is not, at root, about these social difficulties, nor about language delays and narrow interests. In fact, most specialists now almost admit as much: they recognize the heterogeniety of the hundred's-of-thousands of cases of which they are aware, and that these cases, taken together, encompass a very wide range of characteristics---so wide, in fact, as to belay the nature of those who have the disability: fully human. What is not so easily seen is that this disability is all TOO human. Your trouble on stage was not a difficulty relating to what the people in your audience felt, thought, believed, and expected. Yet, your trouble had very much to do with what they did expect.

Autism is not a simple disability like blindness, amputation, or intellectual disability. Nor is it a simple insult to understand, like a broken leg, a burn, or lung cancer. In fact, autism may be as complex and deep as simply being human. Fortunately for you, your debilitating stage fright---and thus your autism---was temporary. But, it was temporary for a very important reason: the context in combination with which your debility arose was temporary; the stage is not your life. Moreover, the temporality of that context is special and formal, unlike normal human social activity. Your behavior was definitely autistic within the positive social expectations of that context. Autism, and its causal debility, are to be understood as being defined by the context, whether or not that context is enduring. Autism is not necessarily the developmental form which most people assume by the term. Autism proper is the general category, while 'temporary' and 'enduring' are its two immediate sub-categories. The latter sub-category, 'enduring', includes---but is not limited to---developmental autism.

The study of developmental autism is still in its infancy. In 'the earlier days' of autism research (twenty-five and more years ago), so few children suspected by their caretakers to have an unusual mental, social, auditory, or linguistic disability had yet been brought to a doctor to be diagnosed. Consequently, the definition of autism as a disability was rather more narrow and superficial than it is today. Today, there are many insightful ideas as to the exact neuropsychological nature of autism. Perhaps the three most prominent of these are the 'Extreme Male Brain' theory of Simon Baron-Cohen, the 'Intense-World Theory' of Henry Markram, and the 'Empathy Imbalance Hypothesis' of Adam James Smith. I'll explain these ideas a little later in this paper. For now, suffice it to say that none of the ideas thus far produced to explain autism are doing more than mapping the boundary within which resides the heart of the disability.

To call autism a disability is a bit like calling a left-arm amputation 'extreme right-handedness'. The problem facing researchers and parents alike is that the injury, or the disability, is as invisible as is the psyche itself. If the human body were itself invisible, and in such a way that nothing could be known about it except through what it does upon visible things, then one would hope that if you lacked a left arm, people wouldn't insist that you are uninterested in picking up a beach ball or in giving a friend a bear hug.

The human organism, in order to survive, must make, and maintain, a perception of the distinction between itself and its environment. This is because it must be able to identify, monitor, and act effectively in the interests of, itself as distinct from its perceptions of its environment. While all environments are essentially dynamic, involving change, progression, and cycles, it is the level of integrity at which an organism can easily-and-automatically maintain itself which constitutes the distinction between what is, for it, static, versus dynamic, forces. The ability to maintain integrity within the dynamic pressures of environment is what may be called 'dynamic autonomy'----and which may be a function of metabolism. What you experienced in your debilitating stage fright was an overwhelmed dynamic autonomy----specifically, the personal-cognitive/social facet of that autonomy. Autism is a basic mechanism of the organism's function of self-preservation, both as a behavioral result of, and as a basic coping mechanism against, the environmental pressures which cause an anti-integrity imbalance between self and other, between core abilities and environment. Many cases of PSD (Post-Traumatic Stress Disorder) in developmentally normal persons involve this mechanism.

Developmental autism is defined as the activation of the autistic mechanism by way of a chronic enfeebling of the immature person's dynamic autonomy, such that some of the person's neurological functions are overwhelmed by various parts of the normal dynamic environment in such a way as to force those functions to withdraw into sub-par, non-normal functioning for such a cumulative duration that the person fails to develop normally within that time-frame. In short, developmental autism is caused by an enduringly oppressed-or-overwhelmed dynamic autonomy (ODA) by way of an enfeebled dynamic autonomy (EDA). ODA is what you would have if you could not escape the stage no matter how long your debilitating stage fright lasted, even though you, as a normal person, do not have much, if any, EDA.

DETERMINING INTENT

There is a widely held belief that persons with autism spectrum disorders have an excess of personal autonomy. One part of the reason for this belief is that the outstanding behavior marking these disorders is a general indifference to the social world (notice the prone-ness here to a casual conflation of the behavior with its assumed motive). Another part is the very term itself: 'autism'. It suggests that persons given the label of 'autistic' are necessarily, immediately, and exclusively self-absorbed, and thus must be taught to relate to others.

The term 'autism' was coined to describe the characteristic non-social behaviors of certain persons. But, at that time, little was known of the underlying cause of these behaviors. Why did these persons prefer to act alone in their own little worlds? Why did they wish to avoid interacting with others? Consequently, the term came to be used to denote an actual disability---or, at least, the notion of one. The notion was that these persons had a poor over-all sense of others, especially of what others felt. After all, human social behavior is driven by emotions of relatedness to others: of wanting to relate to others, and of wanting to be related to. So, the label of 'autistic' helped solidify the impression that these persons lacked the general, 'other'-oriented empathy which is most naturally assumed to be the singular key to normal social ability.

But, perhaps the most critical reason for the belief that persons with autism spectrum disorders have an excess of personal autonomy is because they do, in fact, seem to lack the instinctive social ability which normal persons take for granted. In fact, it has been demonstrated, countless times, and in all kinds of settings, that these persons are unable readily to negotiate the social world. Such an inability suggests a lack of a basic knowledge of the common-sense rules of human interaction. Consequently, much effort has been spent developing techniques to teach persons with autism spectrum disorders how to interact with others, including techniques that involve explicit instruction in these common-sense social rules (can you spell 'micro-management'?). But, without knowing what actually drives autistic behavior, it is impossible to ascertain whether these techniques are not actually counter-productive to their own ideal ends. When persons thought to need to be taught more-or-less like computers are actually overwhelmed by their concern for what others wish of them, the teaching becomes a self-fulfilling prophecy.

This 'self-fulfilling prophecy' of micro-managed instruction is exactly the problem in my own case. For example, I often cease to have a learning-relationship with some machine while being directed by someone to follow their active instructions on how to operate the machine. My sense of the machine's dynamics in relation to me are obliterated by my need to focus on the person's instructions. My inability to learn directly from the machine while following live, micro-managed instructions in its operation is like what you might experience if each of two different persons is simultaneously talking to you about how their own day went: you might find that you cannot pay attention to both person's tales at the same time: one's tale becomes background noise the moment you shift your attention to the other's. If you have this problem, and if they both then escalate their respective efforts to gain or hold your attention, then you even may find that your mind shuts them both out. Many parents of multiple children occasionally experience something of this problem. It can feel a lot like 'being a frog': your two eyes each trying to look in the opposite direction of the other, each looking straight at something on opposite ends of your field of vision. In short, 'you can't serve two masters', at least not each fully at the same time.

Also, in my case, my entire mind and psyche is often so at the mercy of anyone who, while in conversation with me, expresses opinions or feelings that are not my own. It's I'm getting hit in the chest with a huge truck every two seconds. My whole sense of reality is changed, again and again, including my sense of myself, my identity, my duties and rights, and my place in that reality. It is sometimes very unpleasant to say the least, especially when I am aware, in my vague way, that the person has ideas about me that are uncharitable-and-mistaken. The basic problem is magnified by the fact that, in being so helplessly hyper-focused on other persons and their opinions, my socio-linguistic and cognitive-empathy responses to these people are often exactly what the person expects per their misconceptions of me. To contradict them would require far more autonomous social energy than I often have. And, even had I such energy, an effort to correct their misunderstandings of me would only bring on arguments that I simply cannot afford to get into per the distress I already experience from these people. In short, I'm never given the 'middle-ground'---or diplomatic---means of approach. In writing by myself, with no vicarious, or other, pressures from another human being, I'm able to think, and to fix my thinking visually. So, in writing, I establish my own, independent understanding, and my own reality, as being properly mine and a part of me. But, I usually cannot recall more than a few tiniest bits of my writing when I'm in the presence of others who are talking to me or expecting things from me. Before age twenty-five, when I began writing, I was virtually blind to myself in any but the most vaguely undetailed ways. I was 'all feeling and action', and 'no mind'. Writing is my only means of a middle- ground with the human world, because it is so easy for others to take control of me because I'm just so empathic. I've so often learned too late that I should not have been so trusting.

I instinctively relate very well to other people---in their own terms---while in close contact with them. And, I react with great energy and competence to others' in-person expectations of me. But, this gives normal people the impression that I'm highly competent to make my own way in the human world. It sure gave that impression to my first employer, who, as a highly driven salesman-entrepreneur, identified me and my then-facilities as just what he needed to get his little business off the ground. It was because of his aggressive, unkindly manner toward my initial, innocently feeble refusals to work for him that I ended up not simply working for him, but focusing myself so intensely and instinctively on his implicit preferences regarding me as his first-and-primary employee that I quickly became thought by him as a copy of himself, including his general outlook, motivations, and personality. He had two grown daughters, but no sons, and I became like an ideal son in his eyes. He kept insisting that he and I were business partners, and that what I was doing by working for him was owning my own business. But, I did not, by my very nature, own any business, nor was I an entrepreneur. Long story short, I quickly became thought of by everyone, including my employer, my mom and dad, and by my mom and dad's whole [derogatory language redacted] church, as a budding socio-economic superman.

It was that church's pastor who thought that since 'superboy' was ostensibly submitted to his spiritual leadership, all 'those other churches' would soon have to cower to that pastor's supposedly [offensive language redacted], and [offensive language redacted]. But, I was the last person to know that I was thought of so highly. I assumed that the way I was treated was the way these people treated all their young people: with great love. But, my health so suffered from my employer's regime that it's increasingly poor state finally induced me to realize I had the force of an excuse to take refuge from everyone on the weekends (away from employers, family, and especially that damned church which I yet knew of only as my socio-cultural universe despite that the pastor insisted anyone there was free to go if they so choose). Only after years-of-weekends, and of many sleepless nights during the workweek, functioning alone, as ME, did it slowly, little piece by little piece, occur to me that I was thought of as a 'great, over-all competent-and-motivated, in-all-things highly intelligent, 'somebody'. After many years of many insults, both from that church-and-its- pastor and from my then-employer (who was especially greedy in all things), one of greatest insults came; it was to my complete, but feebly-felt surprise, that the head elder of that [derogatory language redacted] church implied to me his take-for-granted-belief that I was both proud of my intellect and valued it far above anything else (including above 'the heart', or good-will intention). To that elder I say many things, but right here I say to him this: Sir, you [derogatory language redacted], I barely even know that I HAVE an intellect, partly thanks to you and your [offensive language redacted] ways. All I was doing, all those years of 'superman-hood', was trying to stay both alive and sane at the same time. It was NEVER obvious to me that it was not obvious to you as to what a distressed state I was in and why, nor that I was not any sort of entrepreneur, nor that it was not me who wrote that note, read by your 'pastor' during one Sunday morning's announcements, saying I was hiring for my business. That note which, like the one in 'Harry Potter and the Goblet of Fire', both ruined my life and kept it from being even more ruined had I found myself instead looked on by you and your church as the timidly feeble, easily manipulated, readily dominated-and-approachable person that I am. To your personal, worldly credit, it was your own once-associate pastor's wife who finally 'flipped out' for having so dutifully internalized your whole [derogatory language redacted] church's notion of 'Christian excellence' that her own husband believed she was [offensive language redacted]. I can only imagine what happened to her and where she is now. You never allowed her any truly personal margin (much less an amount and manner sufficient to her). You never gave her an option of a middle-ground. I was merely lucky that my name was, as it were, entered in the Goblet of Fire.

The 'middle-ground' of approach is potentially contentious, or otherwise disharmonious, relationships is analogous to what a band of 'Indians in the movies does when it finds itself in a state of mutual recognition with another band at some distance from itself: It will at first stop, and hold its ground, and then will approach to a point halfway to the other band, and stop. This allows the other band the option to engage, or not engage, in close contact, as, and in the manner in which, it wishes: standing its ground, or approaching, or departing.

There is a lake in south-central Massachusetts commonly called Lake Webster. But, on many maps, this lake is instead labelled with its American Native name: Chuabunagungamaug. Actually, this label is only the latter half of the full Native name: Chargogagogmanchaugagogchaubunagungamaug. It means "You fish on your side, we fish on our side, nobody fishes in the middle".

Williams syndrome (WS) is characterized by seemingly contradictory behaviors. On the one hand, it features high-level language skills, and some very positive social behaviors. On the other hand, it features disturbed behavior, and learning difficulties.

Normal= baseline heart signal with dynamic, balanced, beat signals above and below the line; Williams syndrome is partly extremely above baseline, and some below. Autism, in most cases, is even more above baseline that WS (Smith, EIH) and some below.

This is a mark of Williams syndrome, which itself is within the spectrum---or ocean---in which developmental autism resides. While Williams syndrome almost always involves an abnormally high level of emotional empathy, the behavioral characteristics of autism have traditionally given the impression that autism is usually caused by a low level of this empathy. The truth is that most cases of autism are actually even higher in emotional empathy than Williams syndrome

It is not obvious to me that it is not obvious to you...

Smile the world, or my own reality, into good, I felt good so I expected my life to become good and full. In keeping with Smith, Markram, and others, it is conceivable that autistic behavior in persons with developmental autism is driven not by an excess or personal and general autonomy, but by a severe lack of it. I, personally, am convinced that this is the case---in every case. In my own case, (which, for reasons all of which are at once vague and obvious to me, has never yet been officially diagnosed by an autism specialist, much less by a duly wide number of them given the tendency of many doctors to be opinionated, and poorly-educated, SOB's) if there are other, normal (and thus, to me, god-like) persons in my effective residence or exist-ence, I am easily trapped from doing as I need to to simply by the general, non-other-human stimuli, including the weather, my tactile sense of being insufficiently bathed, my clothes in general, a cot on which I may be lying, my body odor, the state of the foreign-soiled state of the restroom, etc..

One of the first to shake the field of autism research, Baron-Cohen's idea is that autism is somehow a function of the cognitive propensities characterisitic of human males, specifically the tendencies of systemizing and narrow focus. He recognized that the behaviors and abilities in autism were partly characterized by these same male tendencies, and that it did not seem to involve the wholistic thinking, and emotional empathy, of human females. Baron-Cohen also pioneered in research that confirmed that autistic person's lacked an adequate sense of the fact that other persons have minds which are functionally independent of their own and thus which are capable of having points of view which the autistic person does not directly have (called the 'Theory of Mind', or ToM, problem). It is the extreme systemizing ability, along with the extreme ability of narrow focus, that partly explains the savant abilities often present in autism. It is the extreme narrow focus that, in part, accounts for the fact that many persons with an autism spectrum disorder have a markedly low sensitivity to various stimuli, and which, when this involves social stimuli, and in light of the ToM problem, partly accounts for their lack of common sense regarding dynamic social rules which normal persons understand instinctively.

Markram's idea is that autism may at least partly be a function of an intensely aversive perception of the world, involving a hyper-responsive amygdala (the brain's management-center for emotion and for general sensory input). Markram's ground-breaking---if decidedly un-Kosher---neurological research suggested that persons with autism must experience various normal stimili far too intensely and thus are forced to withdraw from the stimuli. But, this theory seems not to account for the cases involving low sensitivity to stimuli and, or, a lack of the instinctive understanding of social rules.

Smith's idea is that autism may, ironically, be caused by the exact opposite of what normal person's initially imagine from the social behavior for which the term 'autistic' was coined: normal persons initially get the impression that autistic persons, by their markedly non-social tendencies, must lack the emotional empathy which drives normal, pro-social behavior. Smith's research, in keeping with Markram's 'Intense-World Theory', has shown that, in fact, this impression is very often exactly the reverse of what is actually experienced by many autistic persons. Smith has further shown that, in keeping both with Baron-Cohen's 'Theory of Mind' research and Markram's own theory, autism often involves an empathic imbalance: over-arousal of direct emotional empathy (such as seen on other's faces or body language, or heard in other's voices), and a poor ability to infer other's invisible mental states [[[[in real-time]]]].

But, all these things (extremes of systemizing and narrow focus, hyper- and hypo-sensitivities, and empathic imbalance) can be accounted for by a single, rather deeper cause. While they all often are involved in developmental autism, not one of them is even part of the deeper problem. This is because autism is not the problem. Autism is not a disability. Autism is a behavior. It is critical to see---and to keep seeing---this distinction.

But, while EDA is what drives the behaviors in developmental autism, EDA does not necessarily result in autistic propensities any more than does ODA. For the normal population, who do not have EDA, ODA can actually make you so respond as demanded that you are captive to continue even if you would otherwise, say, be rushing off to take a pee, or to get some very needed sleep. The integrity of human society in an imperfect world depends on parents' empathic willingness to sacrifice their personal convenience for the needs of their helpless or otherwise vulnerable offspring. The disability of autism involves a basic drive to interact with the environment, including both its social and non-social elements. This is why, for example, you are capable of experiencing stage fright even though you have no thought that audience might even so much as be day-dreaming of killing you. But, developmental autism, below a certain level of development, may not usually, if ever, involve the aversive experience that normally occurs by way of ODA; the EDA at that level may be so thorough. This is general or total absence of aversion is logically in developmental autism because even more-developed stages of autism often involve non-aversive disordered experiences. But, most interesting here is the gender disparity in the incidence of developmental autism: it afflicts as much as five times more boys than girls. The distinction of autism as a set of non-social behaviors suggests that this disparity is not all that it seems to be. Good bye, Norma Jean, Heath Ledger, etc.

According to Donna William’s account of her autism (in her four books, beginning with 'No One, Nowhere'), the underlying disability causing 'autism' (autistic behavior) appears to be an inability fully to process dynamic sensory and, or social, stimuli concurrently with how this stimuli dynamically effects the self. In normal development, the self is more-or-less dynamically equal to the dynamic stressors of environment, allowing the person to adapt, grow, and mature. But, in the disability causing autism, everyday dynamic stressors are, in effect, overwhelming to dynamic personal autonomy, preventing the person from sufficiently adapting.

Autism thus appears to stem from something analogous to the 'jelly legs' which a young woman might experience in her first dance with her 'dream boy': she may be so overwhelmed by his special presence-and-attention that she has too little brain-power left to manage her own part in the dance. She may stumble, or even fall; and she may become so embarrassed or frightened by her poor performance that she suddenly bursts into tears and runs off to hide in the bathroom. The problem she is having is what I call an overwhelmed dynamic autonomy: she is effectively so disabled by her emotions toward the boy that she is unable continuously to re-adapt to the demands of the dance.

Autistic persons are noted to have difficulty perceiving a distinction between themselves and their environment. But, this difficulty is not unique to autistic persons. In fact, virtually all normal persons have a certain difficulty perceiving a distinction between themselves and their environment---though often not in the same ways as have autistic persons.

Interestingly, many a thing about which normal persons have difficulty perceiving a distinction between themselves and it are things about which autistic persons often have little or no such difficulty. Consider the fact that normal persons commonly fail to distinguish between their visual perception of the world and the actual state of the world. Normal persons commonly start out by assuming that their visual perception does not merely represent the world but is part of what the world actually is. Contrary to your end-state subjective visual experience of the world, your visual perception is not immediate or direct, nor is it the result of a simple process.

The world does not, in itself, have an image or appearance, any more than, say, an apple has a taste, or than the electronic speaker system in a conference hall has an understanding of the spokesman's words which it is reproducing. There is no image in the world; there is no taste going on in the apple; and there is no sentient mind in the electronic speaker system. Does a British accent have a native Chinese ear, an American ear, or the 'plain, flat, accent-less' ear of a British person? Does a hot stove burn itself and feel pain? Does a cool summer breeze relieve its hot, sweaty body? Does a joke find humor in itself so that it would laugh if only it had a mouth?

Your eyes are not windows from out of which you see the world, they are specialized organs for transmitting light to your optic nerve which, in turn, reacts by sending impulses to your brain. These impulses are in the 'language' which your brain understands: electricity. Your brain processes the electrical information of the optic nerve---and in a very complex way---, the end-result of which is that you have a visual experience.

But, let's say that your brain were too feeble in its job of processing the information of your optic nerve. In other words, that your brain's visual-processing autonomy is effectively weaker than the electric-impulse autonomy of your optic nerve (autonomy is another word for functional distinction). In this case, your brain's visual processing would be overwhelmed by your optic nerve, making your visual experience commensurately incoherent, and possibly even causing you a psychic sense of distress or lack of control.

Important to understanding autism and its cause is the fact that your brain, in 'doing the seeing', is pro-active and aggressive. It does not simply sit back and hope the optic nerve will make the picture. There thus is a balance, or teamwork, between your brain and your optic nerve: your brain acts with a forcefulness that is in some sense equal the forcefulness of the impulses of the optic nerve. If your brain does not act aggressively enough, then your visual experience will be one of a jumbled, or even 'pixilated', picture. Your brain must act not only in concert with your optic nerve, but must in some sense act autonomously from it. Your optic nerve does not see, nor can it make your brain see. Your brain must have the kind of energy...to make itself...see.

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Note: Personally Identifiable Information (PII) has been redacted in this document

Daniel Pech

November 16, 2009

Subject: SIGNS: Seeing The Miracle in Autism (Draft-in-progress #14)

(Originally sent to [PII redacted], who has a mention of your Guild on his website.)

Please, if you would, I would be very grateful for a response, as I am in great need of help. Thank you for your chapter in 'Musicophelia' about people with Williams Syndrome (WS). I just read that for the first time yesterday evening. I've done some research---and deep contemplation---on my own case, and had independently concluded that I have both WS and ASD (only three-and-a-half years later did I happen upon anything whatever that said that this combination was possible (STOJANOVIK, V. 2006), and then just last week found another (Smith, 2006).

SIGNS by Daniel Pech, copyright November 2009 [PII redacted]

"Tell Graham...tell him.......see." ---------SIGNS, starring Mel Gibson and Joaquin Phoenix
Only a non-random entity can have a concept of randomness. In other words, the mark of intelligence is making important distinctions---or seeing the signs. ---------Daniel Pech

ABSTRACT

There is a widely held belief that persons with autism spectrum disorders possess an at least normal level of personal autonomy---a belief based in part on these person's pointedly self-absorbed behavior. Additionally, there is a widely held belief that autism, and its causes, are distinct from various other neuropsychological disorders and their causes, such as schizophrenia, Williams syndrome, and Borderline Personality Disorder. Finally, there is a widely held belief that autism is strictly neurodevelopmental in nature. The present article argues that all three of these beliefs are mistaken. This argument is made by observing three things. 1.) In a society dominated by normal persons, and these dominated by males, it can be expected that abnormal or otherwise disadvantaged persons will have the greatest difficulties in life---especially if their disadvantages are misunderstood or unrecognized. 2.) The appearance of doing well in life does not prevent 'normal' persons from experiencing mid-life crises, burnout, confusion, and even addictive, repetitive, or reclusive patterns of coping. 3.) Autism is a behavior driven by a disability, and both the behavior and the disability occur in the normal population.

FIRST SIGHTING

Your heart pounds in your ears as you walk on stage. But, you find an approving audience, so you happily reach for the microphone. Suddenly, your throat tightens; you can't speak. Your mind freezes in fear and goes utterly blank. You break out in a cold sweat, and the pressure rising in your face feels like it is about to explode. Suddenly, you can't bear it any longer, and you stiffly walk off-stage, and hide in a back room. How did this happen? If the crowd were unfriendly, even willing to hurt you physically, then your debilitating stage fright would be immediately understandable. Yet, this happened to you with a friendly audience. You are your own person, so, on the face of it, your debility is a paradox. It's not logical; it's not reasonable. There you were, about to speak, then it all closed in on you. Why?

Some people will answer that the reason you were unable to function linguistically and mentally while on stage was because your fight-or-flight response was so fully activated. That is, your fear of speaking to an audience so overwhelmed your 'finer' abilities (such as speech and thought) that you became unable to function as the anticipated speaker, but were able still to flee the stage. But, this does not actually answer the question. The fight-or-flight response is a symptom, not a cause. And, in your stage fright, it was being activated by something. The question is, BY WHAT?

As a social creature, you are capable of being emotionally effected by the expressed feelings of other persons. This includes both overt and subtle expressions, and involves the whole range of emotions: anger, joy, etc.. It also involves whether or not these emotions are directed at you in terms of what those persons think of you ("He's so lame", or "Yeah, he's so right, the cop was clearly being a [offensive language redacted]"). But, if this is so, then it can be expected that formal social gatherings, by their formal nature, would have a dimension of power that informal gatherings have not. In fact, formal gatherings do have this power, and it is a function of the cumulative effect which all those persons have on a given one of them. Virtually each person imputes much, if not most, of that collective power into the expressions of each person there. This is why, for example, a large audience is more dynamic than a small audience, especially if the members of the small one are disappointed for having expected a large one.

Your stage fright (or your radio talk-show fright) is caused by your sincerely inferred imagination of the cumulative expectation of the more-or-less formal audience. This is so even if you cannot see or hear the audience---or, if, unknown to you, there actually is no audience, since, in the past, you've either experienced or inferred the cumulative power of a crowd. In the case of your debilitating stage fright, your independent social faculties were so outweighed by your imagination of the crowd's cumulative expectation that you were unable to ignore it sufficient to function as your own person. The cumulative expectation of the audience was palpable---at least to you--so it overwhelmed your congruent sensibilities (speech and thought) while leaving your other sensibilities relatively intact (including vision, decision-making, and bipedal locomotion).

Now, all this may seem a bit odd to those who, despite having themselves been on stage, have never really suffered stage fright. But, the far odder thing would be if no one in that audience of yours had ever heard of---or even experienced---stage fright. In that worst case, they would have found your behavior incomprehensible: you utterly failed to behave socially as they had hoped, and they cannot see why you behaved the way you did. But, regardless of what the crowd thinks, your behavior was, by definition, autistic. That's what I said: autistic. It may have been temporarily so, but it was definitely so.

EXTINGUISHING SELFISH IMPRESSIONS

Autistic persons are noted to have difficulty perceiving a distinction between themselves and their environment. Most of them can't see a clear difference between their experiences and the external processes and agents involved in their experiences. Many of them seem to think that the way they are effected by objects or persons outside themselves actually are a part of those objects or persons.

But, the difficulty of perceiving a distinction between self and environment is not unique to autistic persons. In fact, virtually all normal persons have this difficulty. A classic case is the conscious science of sight. Even in the 'Scientific Age', normal persons commonly fail to distinguish between their visual perception of the world and the actual state of the world. They commonly start by assuming that their visual perception does not merely represent the world, but is part of what the world actually is. In other words, since their ability to do things in the world by way of their sight is so dependable, they get the impression that the world itself has an image, or an appearance.

Contrary to your end-state subjective visual experience of the world, your visual perception is not immediate or direct. Nor is it the result of a simple process. Your eyes are not windows from out of which you see the world, they are specialized organs for transmitting light to your optic nerve which, in turn, reacts by sending impulses to your brain. These impulses are in the 'language' which your brain understands: electricity. Your brain processes the electrical information of the optic nerve---and in a very complex way---, the end-result being that you have a visual experience.

The world does not, in itself, have an image or appearance, any more than, say, an apple has a taste, or than the electronic speaker system in a conference hall has an understanding of the spokesman's words which it is reproducing. There is no image in the world; there is no taste going on in the apple; and there is no sentient mind in the electronic speaker system. On a similar note: Does a British accent have a native Chinese ear, an American ear, or the 'plain, flat, accent-less' ear of a British person? Does a hot stove burn itself and feel pain? Does a cool summer breeze relieve its hot, sweaty body? Does a joke find humor in itself so that it would laugh if only it had a mouth?

The difficulty of perceiving a distinction between self and environment bears upon the normal person's problem of understanding autism. Most normal persons today, including most specialists, commonly hold the notion that the usual behavioral signs of autism more-or-less ARE the disability. And, commonly considered to be the key behavioral signs of the disability are difficulties relating to others, language delays, and narrow interests. But, the disability of autism, just like your stage fright, is not, at root, about these social behaviors---which also means that it is not, at root, about language delays or narrow interests. Many persons who have stage fright nevertheless are able to perform; while others, who may or may not have stage fright, actually come to depend, for their sense of self-worth or even self- concept, upon the approval of the audience. Many autism specialists now admit that autism is virtually always used in a vague way, that it fails to make a distinction between behavioral abnormalities and the experiences which compel those behaviors. Normal persons commonly characterize autism as a person's being so singularly self-absorbed as to be unaffected by other's feelings and to be unable to see from another's point of view. But, this characterization is made from the normal point of view---just like that of your stage fright by your worst-case audience---, including how normal persons are socio- emotionally most readily affected by the behavior of autistic persons. The insistence by normal person's on using their own normal frame of reference to judge the social psychology behind autistic behavior is what is so singularly self-centered: it is unable to see what is so often actually there.

Your trouble on stage was not from a difficulty in relating to what your audience expected. It was from feeling their expectation all too much. The only saving grace for your failure to perform as expected was that your audience understood the cause of your behavior. Had none in your audience so much as heard of stage fright, much less experienced it, then they all would have misidentified your intent by way of their own privileged point of view: they would have assumed that your intent looked basically the same as your behavior; that you were indifferent, even displeased, with to their desire to hear you talk. But, the most telling point here is that had your audience been so ignorant and self-centered, and had you had to go on stage to such an audience repeatedly, then you might in fact have developed the displeasure which they initially imputed. In other words, you would have developed a sense of being used more-or-less as a puppet for the pleasure of the audience. You might then have withdrawn entirely from an otherwise promising career which involved public speaking.

DETERMINING INTENT

The study of developmental autism is still in its infancy. In 'the earlier days' of autism research (twenty-five and more years ago), so few children suspected by their caretakers to have an unusual mental, social, auditory, or linguistic disability had yet been brought to a doctor to be diagnosed. Consequently, the definition of autism as a disability was rather more narrow and superficial than it is today. Today, there are many insightful ideas as to the exact neuropsychological nature of autism. Perhaps the three most prominent of these are the 'Extreme Male Brain' theory of Simon Baron-Cohen, the 'Intense-World Theory' of Henry Markram, and the 'Empathy Imbalance Hypothesis' of Adam James Smith. I'll explain these ideas a little later in this paper. For now, suffice it to say that none of the ideas thus far produced to explain autism are doing more than mapping the boundary within which resides the heart of the disability.

To call autism a disability is a bit like calling a left-arm amputation 'extreme right-handedness'. The problem facing researchers and parents alike is that the injury, or the disability, is as invisible as is the psyche itself. If the human body were itself invisible, and in such a way that nothing could be known about it except through what it does upon visible things, then one would hope that if you lacked a left arm, people wouldn't insist that you are uninterested in picking up a beach ball or in giving a friend a bear hug.

Fortunately for you, your debilitating stage fright---and thus your autism---was temporary. But, it was temporary for a very important reason: the context in combination with which your debility arose was temporary; the stage is not your life. Moreover, the temporality of that context is special and formal, unlike normal human social activity. Your behavior was definitely autistic within the positive social expectations of that context. Autism, and its causal debility, are thus to be understood as being defined by the context, whether or not that context is enduring. Autism is not necessarily the developmental form which most people assume by the term. Autism proper is the general category, while 'temporary' and 'enduring' are its two immediate sub-categories. The latter sub-category, 'enduring', includes---but is not limited to---developmental autism.

The human organism, in order to survive, must make, and maintain, a perception of the distinction between itself and its environment. This is because it must be able to identify, monitor, and act effectively in the interests of, itself as distinct from its perceptions of its environment. While all environments are essentially dynamic, involving change, progression, and cycles, it is the level of integrity at which an organism can easily-and-automatically maintain itself which constitutes the distinction between what is, for it, static, versus dynamic, forces. The ability to maintain integrity within the dynamic pressures of environment is what may be called 'dynamic autonomy'----and which may be a function of metabolism. What you experienced in your debilitating stage fright was an overwhelmed dynamic autonomy----specifically, the personal-cognitive/social facet of that autonomy. Autism is a basic mechanism of the organism's function of self-preservation, both as a behavioral result of, and as a basic coping mechanism against, the environmental pressures which cause an anti-integrity imbalance between self and other, between core abilities and environment. Many cases of PTSD (Post-Traumatic Stress Disorder) in developmentally normal persons involve this mechanism.

Developmental autism is defined as the activation of the autistic mechanism by way of a chronic enfeebling of the immature person's dynamic autonomy, such that some of the person's neurological functions are overwhelmed by various parts of the normal dynamic environment in such a way as to force those functions to withdraw into sub-par, non-normal functioning for such a cumulative duration that the person fails to develop normally within that time-frame. In short, developmental autism is caused by an enduringly oppressed-or-overwhelmed dynamic autonomy (ODA) by way of an enfeebled dynamic autonomy (EDA). ODA is what you would have if you could not escape the stage no matter how long your debilitating stage fright lasted, even though you, as a normal person, do not have much, if any, EDA.

There is a widely held belief that persons with autism spectrum disorders have an excess of personal autonomy. One part of the reason for this belief is that the outstanding behavior marking these disorders is a general indifference to the social world (notice the prone-ness here to a casual conflation of the behavior with its assumed motive). Another part is the very term itself: 'autism'. It suggests that persons given the label of 'autistic' are necessarily, immediately, and exclusively self-absorbed, and thus must be taught to relate to others.

The term 'autism' was coined to describe the characteristic non-social behaviors of certain persons. But, at that time, little was known of the underlying cause of these behaviors. Why did these persons prefer to act alone in their own little worlds? Why did they wish to avoid interacting with others? Consequently, the term came to be used to denote an actual disability---or, at least, the notion of one. The notion was that these persons had a poor over-all sense of others, especially of what others felt. After all, human social behavior is driven by emotions of relatedness to others: of wanting to relate to others, and of wanting to be related to. So, the label of 'autistic' helped solidify the impression that these persons lacked the general, 'other'-oriented empathy which is most naturally assumed to be the singular key to normal social ability.

But, perhaps the most critical reason for the belief that persons with autism spectrum disorders have an excess of personal autonomy is because they do, in fact, seem to lack the instinctive social ability which normal persons take for granted. In fact, it has been demonstrated, countless times, and in all kinds of settings, that these persons are unable readily to negotiate the social world. Such an inability suggests a lack of a basic knowledge of the common-sense rules of human interaction. Consequently, much effort has been spent developing techniques to teach persons with autism spectrum disorders how to interact with others, including techniques that involve explicit instruction in these common-sense social rules (can you spell 'micro-management'?). But, without knowing what actually drives autistic behavior, it is impossible to ascertain whether these techniques are not actually counter-productive to their own ideal ends. When persons thought to need to be taught more-or-less like computers are actually overwhelmed by their concern for what others wish of them, the teaching becomes a self-fulfilling prophecy.

This 'self-fulfilling prophecy' of micro-managed instruction is exactly the problem in my own case. For example, I often cease to have a learning-relationship with some machine while being directed by someone to follow their active instructions on how to operate the machine. My sense of the machine's dynamics in relation to me are obliterated by my need to focus on the person's instructions. My inability to learn directly from the machine while following live, micro-managed instructions in its operation is like what you might experience if each of two different persons is simultaneously talking to you about how their own day went: you might find that you cannot pay attention to both person's tales at the same time: one's tale becomes background noise the moment you shift your attention to the other's. If you have this problem, and if they both then escalate their respective efforts to gain or hold your attention, then you even may find that your mind shuts them both out. Many parents of multiple children occasionally experience something of this problem. It can feel a lot like 'being a frog': your two eyes each trying to look in the opposite direction of the other, each looking straight at something on opposite ends of your field of vision. In short, 'you can't serve two masters', at least not each fully at the same time.

Also, in my case, my entire mind and psyche is often so at the mercy of anyone who, while in conversation with me, expresses opinions or feelings that are not my own. It's I'm getting hit in the chest with a huge truck every two seconds. My whole sense of reality is changed, again and again, including my sense of myself, my identity, my duties and rights, and my place in that reality. It is sometimes very unpleasant to say the least, especially when I am aware, in my vague way, that the person has ideas about me that are uncharitable-and-mistaken. The basic problem is magnified by the fact that, in being so helplessly hyper-focused on other persons and their opinions, my socio-linguistic and cognitive- empathy responses to these people are often exactly what the person expects per their misconceptions of me. To contradict them would require far more autonomous social energy than I often have. And, even had I such energy, an effort to correct their misunderstandings of me would only bring on arguments that I simply cannot afford to get into per the distress I already experience from these people. In short, I'm never given the 'middle-ground'---or diplomatic---means of approach. In writing by myself, with no vicarious, or other, pressures from another human being, I'm able to think, and to fix my thinking visually. So, in writing, I establish my own, independent understanding, and my own reality, as being properly mine and a part of me. But, I usually cannot recall more than a few tiniest bits of my writing when I'm in the presence of others who are talking to me or expecting things from me. Before age twenty-five, when I began writing, I was virtually blind to myself in any but the most vaguely undetailed ways. I was 'all feeling and action', and 'no mind'. Writing is my only means of a middle- ground with the human world, because it is so easy for others to take control of me because I'm just so empathic. I've so often learned too late that I should not have been so trusting.

I instinctively relate very well to other people---in their own terms---while in close contact with them. And, I react with great energy and competence to others' in-person expectations of me. But, this gives normal people the impression that I'm highly competent to make my own way in the human world. It sure gave that impression to my first employer, who, as a highly driven salesman-entrepreneur, identified me and my then-facilities as just what he needed to get his little business off the ground. It was because of his aggressive, unkindly manner toward my initial, innocently feeble refusals to work for him that I ended up not simply working for him, but focusing myself so intensely and instinctively on his implicit preferences regarding me as his first-and-primary employee that I quickly became thought by him as a copy of himself, including his general outlook, motivations, and personality. He had two grown daughters, but no sons, and I became like an ideal son in his eyes. He kept insisting that he and I were business partners, and that what I was doing by working for him was owning my own business. But, I did not, by my very nature, own any business, nor was I an entrepreneur. Long story short, I quickly became thought of by everyone, including my employer, my mom and dad, and by my mom and dad's whole [derogatory language redacted] church, as a budding socio-economic superman.

It was that church's pastor who thought that since 'superboy' was ostensibly submitted to his spiritual leadership, all 'those other churches' would soon have to cower to that pastor's supposedly incontestably superior wisdom, and effectively omniscient 'spiritual' discernment. But, I was the last person to know that I was thought of so highly. I assumed that the way I was treated was the way these people treated all their young people: with great love. But, my health so suffered from my employer's regime that it's increasingly poor state finally induced me to realize I had the force of an excuse to take refuge from everyone on the weekends (away from employers, family, and especially that damned church which I yet knew of only as my socio-cultural universe despite that the pastor insisted anyone there was free to go if they so choose). Only after years-of-weekends, and of many sleepless nights during the workweek, functioning alone, as ME, did it slowly, little piece by little piece, occur to me that I was thought of as a 'great, over-all competent-and-motivated, in-all-things highly intelligent, 'somebody'. After many years of many insults, both from that church-and-its- pastor and from my then-employer (who was especially greedy in all things), one of greatest insults came; it was to my complete, but feebly-felt surprise, that the head elder of that [derogatory language redacted] church implied to me his take-for-granted-belief that I was both proud of my intellect and valued it far above anything else (including above 'the heart', or good-will intention). To that elder I say many things, but right here I say to him this: Sir, you [derogatory language redacted], I barely even know that I HAVE an intellect, partly thanks to you and your [offensive language redacted] ways. All I was doing, all those years of 'superman-hood', was trying to stay both alive and sane at the same time. It was NEVER obvious to me that it was not obvious to you as to what a distressed state I was in and why, nor that I was not any sort of entrepreneur, nor that it was not me who wrote that note, read by your 'pastor' during one Sunday morning's announcements, saying I was hiring for my business. That note which, like the one in 'Harry Potter and the Goblet of Fire', both ruined my life and kept it from being even more ruined had I found myself instead looked on by you and your church as the timidly feeble, easily manipulated, readily dominated-and-approachable person that I am. To your personal, worldly credit, it was your own once-associate pastor's wife who finally 'flipped out' for having so dutifully internalized your whole [derogatory language redacted] church's notion of 'Christian excellence' that her own husband believed she was [offensive language redacted]. I can only imagine what happened to her and where she is now. You never allowed her any truly personal margin (much less an amount and manner sufficient to her). You never gave her an option of a middle-ground. I was merely lucky that my name was, as it were, entered in the Goblet of Fire.

The 'middle-ground' of approach in potentially contentious, or otherwise disharmonious, relationships is analogous to what a band of 'Indians in the movies does when it finds itself in a state of mutual recognition with another band at some distance from itself: It will at first stop, and hold its ground, and then will approach to a point halfway to the other band, and stop. This allows the other band the option to engage, or not engage, in close contact, as, and in the manner in which, it wishes: standing its ground, or approaching, or departing.

There is a lake in south-central Massachusetts commonly called Lake Webster. But, on many maps, this lake is instead labelled with its American Native name: Chuabunagungamaug. Actually, this label is only the latter half of the full Native name: Chargogagogmanchaugagogchaubunagungamaug. It means "You fish on your side, we fish on our side, nobody fishes in the middle".

Autistic persons have difficulty perceiving a distinction between themselves and their environment, and they have the sense that the way they are effected by objects or persons outside themselves actually are a part of those objects or persons. Partly as a consequence, autistic persons lack an effectively dynamic ability to control their own involvement in circumstances which impinge upon them. When they have a pleasant experience, they are captive to it (this often partly accounts for their ability to focus intensely on one thing for hours or days). When they have an unpleasant experience, they are forced simply to withdraw from it---if they can---, usually either by withdrawing into themselves, or by removing themselves from the physical space which contains the thing causing their unpleasant experience.

Williams syndrome (WS) is characterized by seemingly contradictory behaviors. On the one hand, it features high-level language skills, and some very positive social behaviors. On the other hand, it features disturbed behavior, and learning difficulties.

Normal= baseline heart signal with dynamic, balanced, beat signals above and below the line; Williams syndrome is partly extremely above baseline, and some below. Autism, in most cases, is even more above baseline that WS (Smith, EIH) and some below.

This is a mark of Williams syndrome, which itself is within the spectrum---or ocean---in which developmental autism resides. While Williams Syndrome almost always involves an abnormally high level of emotional empathy, the behavioral characteristics of autism have traditionally given the impression that autism is usually caused by a low level of this empathy. The truth is that most cases of autism are actually even higher in emotional empathy than Williams syndrome

It is not obvious to me that it is not obvious to you...
Smile the world, or my own reality, into good, I felt good so I expected my life to become good and full. In keeping with Smith, Markram, and others, it is conceivable that autistic behavior in persons with developmental autism is driven not by an excess or personal and general autonomy, but by a severe lack of it. I, personally, am convinced that this is the case---in every case. In my own case, (which, for reasons all of which are at once vague and obvious to me, has never yet been officially diagnosed by an autism specialist, much less by a duly wide number of them given the tendency of many doctors to be opinionated, and poorly-educated, SOB's) if there are other, normal (and thus, to me, god-like) persons in my effective residence or exist-ence, I am easily trapped from doing as I need to to simply by the general, non-other-human stimuli, including the weather, my tactile sense of being insufficiently bathed, my clothes in general, a cot on which I may be lying, my body odor, the state of the foreign-soiled state of the restroom, etc..

One of the first to shake the field of autism research, Baron-Cohen's idea is that autism is somehow a function of the cognitive propensities characterisitic of human males, specifically the tendencies of systemizing and narrow focus. He recognized that the behaviors and abilities in autism were partly characterized by these same male tendencies, and that it did not seem to involve the wholistic thinking, and emotional empathy, of human females. Baron-Cohen also pioneered in research that confirmed that autistic person's lacked an adequate sense of the fact that other persons have minds which are functionally independent of their own and thus which are capable of having points of view which the autistic person does not directly have (called the 'Theory of Mind', or ToM, problem). It is the extreme systemizing ability, along with the extreme ability of narrow focus, that partly explains the savant abilities often present in autism. It is the extreme narrow focus that, in part, accounts for the fact that many persons with an autism spectrum disorder have a markedly low sensitivity to various stimuli, and which, when this involves social stimuli, and in light of the ToM problem, partly accounts for their lack of common sense regarding dynamic social rules which normal persons understand instinctively.

Markram's idea is that autism may at least partly be a function of an intensely aversive perception of the world, involving a hyper-responsive amygdala (the brain's management-center for emotion and for general sensory input). Markram's ground-breaking---if decidedly un-Kosher---neurological research suggested that persons with autism must experience various normal stimili far too intensely and thus are forced to withdraw from the stimuli. But, this theory seems not to account for the cases involving low sensitivity to stimuli and, or, a lack of the instinctive understanding of social rules.

Smith's idea is that autism may, ironically, be caused by the exact opposite of what normal person's initially imagine from the social behavior for which the term 'autistic' was coined: normal persons initially get the impression that autistic persons, by their markedly non-social tendencies, must lack the emotional empathy which drives normal, pro-social behavior. Smith's research, in keeping with Markram's 'Intense-World Theory', has shown that, in fact, this impression is very often exactly the reverse of what is actually experienced by many autistic persons. Smith has further shown that, in keeping both with Baron-Cohen's 'Theory of Mind' research and Markram's own theory, autism often involves an empathic imbalance: over-arousal of direct emotional empathy (such as seen on other's faces or body language, or heard in other's voices), and a poor ability to infer other's invisible mental states [[[[in real-time]]]].

But, all these things (extremes of systemizing and narrow focus, hyper- and hypo-sensitivities, and empathic imbalance) can be accounted for by a single, rather deeper cause. While they all often are involved in developmental autism, not one of them is even part of the deeper problem. This is because autism is not the problem. Autism is not a disability. Autism is a behavior. It is critical to see---and to keep seeing---this distinction.

But, while EDA is what drives the behaviors in developmental autism, EDA does not necessarily result in autistic propensities any more than does ODA. For the normal population, who do not have EDA, ODA can actually make you so respond as demanded that you are captive to continue even if you would otherwise, say, be rushing off to take a pee, or to get some very needed sleep. The integrity of human society in an imperfect world depends on parents' empathic willingness to sacrifice their personal convenience for the needs of their helpless or otherwise vulnerable offspring.

Mothers and fathers often find themselves compelled to forgo sleep---and pee breaks---to ensure that their offspring are properly cared for. This kind of compulsion is not an abstract, immaterial force. Nor is it based solely on logic or reasoning. Rather, it is built into the human brain. It's most basic psychological cause, in all cases, is emotional empathy (Smith, 2009). Furthermore, it is not limited to concern for one's own children, nor to children generally. The problem is when this kind of compulsion, whether by conditioning or neurological abnormality, is so intense that it becomes a disability. Enter Marylin Monroe,

The disability of autism involves a basic drive to interact with the environment, including both its social and non-social elements. This is why, for example, you are capable of experiencing stage fright even though you have no thought that audience might even so much as be day-dreaming of killing you. But, developmental autism, below a certain level of development, may not usually, if ever, involve the aversive experience that normally occurs by way of ODA; the EDA at that level may be so thorough. This is general or total absence of aversion is logically in developmental autism because even more- developed stages of autism often involve non-aversive disordered experiences. But, most interesting here is the gender disparity in the incidence of developmental autism: it afflicts as much as five times more boys than girls. The distinction of autism as a set of non-social behaviors suggests that this disparity is not all that it seems to be. Good bye, Norma Jean, Heath Ledger, etc.

According to Donna William’s account of her autism (in her four books, beginning with 'No One, Nowhere'), the underlying disability causing 'autism' (autistic behavior) appears to be an inability fully to process dynamic sensory and, or social, stimuli concurrently with how this stimuli dynamically effects the self. In normal development, the self is more-or-less dynamically equal to the dynamic stressors of environment, allowing the person to adapt, grow, and mature. But, in the disability causing autism, everyday dynamic stressors are, in effect, overwhelming to dynamic personal autonomy, preventing the person from sufficiently adapting.

Autism thus appears to stem from something analogous to the 'jelly legs' which a young woman might experience in her first dance with her 'dream boy': she may be so overwhelmed by his special presence-and-attention that she has too little brain-power left to manage her own part in the dance. She may stumble, or even fall; and she may become so embarrassed or frightened by her poor performance that she suddenly bursts into tears and runs off to hide in the bathroom. The problem she is having is what I call an overwhelmed dynamic autonomy: she is effectively so disabled by her emotions toward the boy that she is unable continuously to re-adapt to the demands of the dance.

Autistic persons are noted to have difficulty perceiving a distinction between themselves and their environment. But, this difficulty is not unique to autistic persons. In fact, virtually all normal persons have a certain difficulty perceiving a distinction between themselves and their environment---though often not in the same ways as have autistic persons.

Interestingly, many a thing about which normal persons have difficulty perceiving a distinction between themselves and it are things about which autistic persons often have little or no such difficulty. Consider the fact that normal persons commonly fail to distinguish between their visual perception of the world and the actual state of the world. Normal persons commonly start out by assuming that their visual perception does not merely represent the world, but is part of what the world actually is. Contrary to your end-state subjective visual experience of the world, your visual perception is not immediate or direct, nor is it the result of a simple process.

The world does not, in itself, have an image or appearance, any more than, say, an apple has a taste, or than the electronic speaker system in a conference hall has an understanding of the spokesman's words which it is reproducing. There is no image in the world; there is no taste going on in the apple; and there is no sentient mind in the electronic speaker system. Does a British accent have a native Chinese ear, an American ear, or the 'plain, flat, accent-less' ear of a British person? Does a hot stove burn itself and feel pain? Does a cool summer breeze relieve its hot, sweaty body? Does a joke find humor in itself so that it would laugh if only it had a mouth?

Your eyes are not windows from out of which you see the world, they are specialized organs for transmitting light to your optic nerve which, in turn, reacts by sending impulses to your brain. These impulses are in the 'language' which your brain understands: electricity. Your brain processes the electrical information of the optic nerve---and in a very complex way---, the end-result of which is that you have a visual experience.

But, let's say that your brain were too feeble in its job of processing the information of your optic nerve. In other words, that your brain's visual-processing autonomy is effectively weaker than the electric- impulse autonomy of your optic nerve (autonomy is another word for functional distinction). In this case, your brain's visual processing would be overwhelmed by your optic nerve, making your visual experience commensurately incoherent, and possibly even causing you a psychic sense of distress or lack of control.

Important to understanding autism and its cause is the fact that your brain, in 'doing the seeing', is pro-active and aggressive. It does not simply sit back and hope the optic nerve will make the picture. There thus is a balance, or teamwork, between your brain and your optic nerve: your brain acts with a forcefulness that is in some sense equal the forcefulness of the impulses of the optic nerve. If your brain does not act aggressively enough, then your visual experience will be one of a jumbled, or even 'pixilated', picture. Your brain must act not only in concert with your optic nerve, but must in some sense act autonomously from it. Your optic nerve does not see, nor can it make your brain see. Your brain must have the kind of energy...to make itself...see.

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Jason Bourret

November 20, 2009

Subject: Behavior analysis and within-subject research

My name is Jason Bourret and I am a Board Certified Behavior Analyst currently serving on the Board of Editors of the Journal of Applied Behavior Analysis (JABA). I do clinical work and conduct applied research at the New England Center for Children (NECC), focusing on skill building and reduction of problem behavior in individuals diagnosed with autism-spectrum disorders. I have attended all of the IACC full committee meetings, services subcommittee meetings, and scientific workshops in person or via webinar and I was particularly interested in the recent discussions of behavior analysis and within- subject research designs.

Given the impact that behavior analysis has had in the field of autism treatment, I am surprised that there isn't a behavior analyst on the committee or the panel of experts selected to speak to issues related to treatment research. You previously noted that there are a number of individuals and groups who would like a seat at the table. It strikes me that the committee would benefit from input from a behavior analyst with experience conducting within-subject research. I suggest the Board of Editors of JABA as a place to find individuals with appropriate qualifications and I, personally, am more than happy to volunteer my time in any capacity to be of assistance.

Also, I would like to extend an invitation to you or any member of the IACC to visit NECC. It is a school for individuals with autism-spectrum diagnoses located in Southborough Massachusetts that has recently been granted an award for enduring programmatic contributions to behavior analysis from the Association for Behavior Analysis' Society for the Advancement of Behavior Analysis. NECC has been providing services for over 30 years and has both day-school and residential services as well as partner classrooms integrated into local public schools. You and the other members of the IACC may find it interesting and informative to see firsthand how a school for individuals with autism operates and to see how the lives of the students can be profoundly impacted through the application of scientifically verified teaching and treatment.

Thank you for your time and best of luck in this important endeavor, Jason

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Eileen Nicole Simon

December 1, 2009

[PII redacted]

Thank you, first and foremost, for allowing me to speak at the meeting held November 21, on the need to investigate: (1) impairment of auditory function as an impediment to learning to speak, and (2) clamping of the umbilical cord at birth, before the first breath, as a factor in cases of neonatal "respiratory depression" that could lead to auditory system impairment.

Following are my thoughts on the issues of vaccine injury, regression, Kanner autism, co-morbid conditions, male vulnerability, and genetics:

Vaccine injury should be included in the research plan, but only with a focus of how thimerosal and other additives might impair brain systems important for language development. The paper by Oyanagi et al. (1988) might be a start [1]. Can the roles of dopamine, serotonin, GABA, methylation and other factors in neurotransmission be shown to be important for synaptogenesis and maturation of the temporal and frontal language areas of the cerebral cortex? The papers by vonHungen et al. (1975) and Kungel & Friauf (1995) could be relevant [2, 3]. Focus on how the insult at time of vaccination affects the brain, and how subsequent maturation might be derailed. Vaccination is important for the health of all children, but why is vaccination needed in the newborn nursery? It might be good to return to the old schedule.

Regression may be too subjective to be taken as solid evidence that vaccine injury caused a sudden loss of preexisting language and motor skills. We watched with baited breath the development of our son [PII redacted]. His brother, [PII redacted], was seriously delayed in rolling over, sitting up, crawling, standing, and walking; and [PII redacted] at Children's hospital told me when he was 21 months old, "He has a mild form of cerebral palsy." [PII redacted] was on-time with all milestones, and he began speaking with clear pronunciation right on time, and in complete sentences! These sentences were exact repetitions of things he had heard others say, and we thought it was because [PII redacted] (who learned to read at 2 years + 2 months of age) loved to read to [PII redacted] and coach him in speaking – I had done a lot of coaching of [PII redacted] because of his slow development of speech and his poor pronunciation. [PII redacted] was also very musical and just before he turned 2 years old could sing all the Christmas carols, including the Twelve Days of Christmas! What a shock when his nursery school teacher suggested at age 3 that he be evaluated for autism. If I had known about regression, I might have grabbed onto this idea as an explanation of [PII redacted]'s failure to develop after the age of 2 or 3. Autism is still not easy to diagnose before 2 to 4 years of age. Regression is a very fuzzy term.

Kanner (1943) began his famous paper stating:

"Since 1938 there have come to our attention a number of children whose condition differs so markedly and uniquely from anything reported so far, that each case merits – and, I hope, will eventually receive – a detailed consideration of its fascinating peculiarities." [4, p217]

The autistic disturbances of affective contact that he described were not seen as commonly as today, and the fathers of four of these patients were also psychiatrists [4, pgs 229, 230, 232, 237]. Barr (1898) reviewed the literature of his day on the rare finding of echolalic speech, which Kanner later referred to as metaphorical and irrelevant [5, 6]. Barr claimed to have examined 1525 cases of mental deficiency but only 2 patients manifested echolalia. Barr's patient, Kirtie, is similar to the cases reported by Kanner – see pp25-29 of Barr's paper, which I have posted at http://www.conradsimon.org/BarrEcholalia1898ocr.pdf. DeSanctis (1908) and Heller (1908) reported cases of "dementia infantilis" using the nomenclature of Kraepelin [7, 8, 9]. Bender (1947) and Yakovlev (1948) described their work with schizophrenic children using the nomenclature of Bleuler [10, 11, 12]. Bender (1955) and Putnam (1955) wrote about psychosis in childhood as a rare condition [13, 14]. Landau and Kleffner (1957, 1960) described aphasia with seizure disorder and damage found post mortem in the auditory pathway, especially the medial geniculate bodies [15, 16]. Childhood psychosis with loss or abnormal development of language was rare in the past. The current increased prevalence appears to be real.

Co-morbid conditions like GI disturbances are common in autism (I work with mentally ill adults, and see GI disorders as a frequent co-morbid condition). [PII redacted] had horrible colic and projectile vomiting during his first year. He also had a "collapsing trachea" especially during sleep, which was often frightening. I think he could have been a case of sudden infant death. [PII redacted] was pale and life-less at birth, slow to begin crying, and he developed jaundice a day or two after birth. GI problems can be the result of brainstem impairment. The article by Windle (1969) on asphyxia at birth made me aware that brainstem damage (especially in the auditory pathway) is the result of the kind of asphyxia [PII redacted] suffered at birth [17]. Multi-organ injury is a common finding in infants who suffer asphyxia at birth [18]

Male/female differences were a surprise finding in my dissertation research on neonatal asphyxia in the rat [19]. At a meeting of the Fetal and Neonatal Society in 2006, the greater vulnerability of males to any perinatal insult became one of the important themes of the meeting. My poster presentations on the historical context of the Apgar score are posted online at http://www.inferiorcolliculus.org/fnps.html.

Genetic disorders are among the many medical conditions associated with autism. I have listed some at http://www.conradsimon.org/WorkingPaper2003.html#GeneticPredispositions. Note that phenylpyruvic and phenylacetic acid metabolites were detected by Folling (1934) before DNA had been isolated [20]. The abnormal metabolites produced by faulty phenylalanine hydroxylase, as well as excess phenylanine could cause breakdown of the blood-brain barrier, and as is the case with bilirubin, the brainstem nuclei of high metabolic rate are more likely to be affected, especially the auditory system [20, 21]. The strategic plan should focus on loci in the brain, not loci of genes on chromosomes.

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[Photo and PII redacted]

Note: Personally Identifiable Information (PII) has been redacted in this document

Eileen Nicole Simon

December 1, 2009

Subject: Autism and birth injury

Thank you. I notice two vacancies on the IACC roster of federal members. I would like to see Dr. Swedo considered for one of these vacancies. Could I also suggest [PII redacted]? He can be contacted at [PII redacted], and I have copied him on this email.

Sincerely,

Eileen Nicole Simon

Note: Personally Identifiable Information (PII) has been redacted in this document

Caroline Rodgers

December 8, 2009

[PII redacted]

I am the author of "Questions about Prenatal Ultrasound and the Alarming Increase in Autism," published in the Winter 2006 issue of Midwifery Today. I am a writer/research who has no financial or professional interest in either autism or ultrasound.

I am concerned that the "Analysis of Public Comments Received in Response to 2009 IACC RFI (Request for Information)" downplays serious concerns expressed by myself and several others regarding prenatal ultrasound's role in causing autism. Under "Question III: What Caused This to Happened and Can This Be Prevented" the heading, "Environmental Risk Factors (Apart from vaccines)," prenatal ultrasound is lumped in with other birth factors in Point 10, specifically:

Investigate birth factors including the use of reproductive technology (e.g., in vitro fertilization), prenatal care, ultrasound exposure, cord clamping, and the use of pitocin/oxytocin during labor, as risk factors in ASD.

A careful reading of all of the public comments regarding these birth factors shows that only prenatal ultrasound and reproductive technology have existing scientific evidence that they may play a role in autism. It is interesting to note that reproductive technology employs ultrasound in many endeavors, including the use of ultrasound to examine, count or monitor ovarian follicle development, examine various female reproductive structures, guide needles used to remove eggs, inseminate or assist in egg implantation. Therefore, prenatal ultrasound is a significant factor in reproductive technology and should be considered a possible risk factor for the higher rate of autism occurring among such high-risk pregnancies.

Scientific studies have shown that:

- **Prenatal ultrasound causes changes in brain formation** in mice similar to those found in autopsied human autistics (Ang, ES, et al. 2006. Prenatal exposure to ultrasound waves impacts neuronal migration in mice. *Proceedings of the National Academy of Science*; 103: 12903).

- **Ultrasound can irreparably harm mitochondria** (Stephens, RH, et al. 1978. Mitochondrial changes resulting from ultrasound irradiation. In: White, DI & Lyons, E.A. ed., Ultrasound in Medicine, New York, Plenum Press, Vol. 4, pp. 591-594), which has been implicated in some autism cases, such as the highly publicized case in which Hannah Poling received an award from Vaccine Court for developing autism following vaccination due to an underlying mitochondrial disorder. (In the Poling case, the mitochondrial disorder was apparently inherited from her mother, but cases of non-inherited mitochondrial disorders also have been linked to autism.)

- A 1982 World Health Organization report, in Section 5. Effects of Ultrasound on Biological Systems, subsection 6.5.4 Human fetal studies summary, said, **"Animal studies suggest that neurological, behavioral, developmental, immunological, hematological changes . . . can result from exposure to ultrasound."** Since that time, significant neurological, behavioral, developmental, immunological and hematological health issues have emerged in the pediatric population, without explanation.

- It is an established fact that elevations in maternal heat during gestation, whether caused by hot tub use, maternal infection or fever, cause various brain defects in offspring. It is also an established fact that the inaudible sound waves emitted by prenatal ultrasound are transformed into heat when they are absorbed by tissue. While doctors commonly claim that prenatal ultrasound does not produce enough heat to harm babies, an article in the April 2008 Journal of Ultrasound in Medicine titled "Fetal Thermal Effects of Diagnostic Ultrasound" cited five studies when it stated, ". . . **there have been several publications showing that diagnostic pulsed ultrasound can produce substantial temperature increases in live perfused fetal brains when insonated in the uterus."**

- There is evidence that autism begins during gestation. Neuroscience Professor Eric Courchesne, of the University of California, San Diego, and Director of the Center for Autism Research at San Diego Children's Hospital, in a 1997 Current Opinion in Neurobiology article on brain abnormalities in autistics, notes that **the fifth week of gestation "may be a 'window of vulnerability' for autism**; the likely etiological heterogeneity of autism suggest that other windows of vulnerability are also possible." (Courchesne, E. 1997. Brainstem, cerebellar and limbic neuroanatomical abnormalities in autism. *Current Opinions in Neurobiology.* 7(2):269-78). This is significant because prenatal ultrasound is now being applied as early as five or six weeks of gestation to confirm pregnancy. If autism begins during gestation, there is all the more reason to thoroughly investigate the role that prenatal ultrasound may play in causing it, as rapid changes in ultrasound technology, gestational windows of exposure, frequency of scans and number of pregnant women undergoing ultrasound have all changed dramatically during the same period of time that autism prevalence has increased exponentially.

Only one scientific study has been undertaken to determine whether prenatal ultrasound causes autism. The retrospective study, "Antenatal Ultrasound and Risk of Autism Spectrum Disorders," was published in September in the Journal of Autism Developmental Disorders. While it concluded that "antenatal u/s (ultrasound) is unlikely to increase the risk of ASD," two experts expressed the following opinions:

1. A fetal ultrasound expert said, ". . . without knowing exposure data (output power, type and length of examination), no conclusion can be drawn. The authors seem to hint that based on their findings (or lack thereof) ultrasound is safe in regards to causing autism but I don't think they can conclude that."
2. A leading epidemiologist said, "The authors did, as they admitted, a simple look at number of scans, which does not take account the doses, and those are more difficult to quantify, of course. They also only showed results of their logistic models when assumed a relationship that

> is essentially exponential, with each additional scan multiplying the odds or risk by a constant factor. There are other ways to analyze those data . . . I wouldn't view this as the last word."

(Not all scientists who reviewed the study found fault with it. Paul Offit said, "I thought the study was quite useful and well done.")

On the basis of the above information, I urge the members of the IACC to act in due diligence to fast- track prenatal ultrasound research. I recommend that the IACC actively seek and fund investigators who will:

- Conduct retrospective studies with carefully matched controls that have had no ultrasound exposure, as there is no proof that the standard "baseline" ultrasound commonly performed between 16 and 22 weeks is without harm. Since, in the absence of national health insurance, not all pregnant women in this country undergo ultrasound scans, there should be a population of unexposed women available for a retrospective study.
- Conduct prospective studies, in which a control population has no ultrasound exposure. (While many scientists balk at the ethics of such a study, it should be possible to find a population of women who choose not to undergo ultrasound and match them with women who do.)
- Broaden ongoing studies that are measuring autism risk factors to include collecting data regarding prenatal ultrasound exposure and analyzing them.
- Correlate gestational times of ultrasound exposure, duration of exams and acoustic output, among other factors, with autism diagnosis, zeroing in on cluster communities.
- Review changes in ultrasound technology and practices, including the expansion of the gestational window of exposure, and how each one might impact embryonic or fetal development.
- Review variations in training hours and standards for all people who conduct prenatal ultrasound exams, which once occurred only in hospitals or diagnostic centers but now occur in doctor offices, commercial "keepsake" portrait studios, abortion clinics and even private homes. While most doctors say that prenatal ultrasound is safe, safety depends upon limiting the thermal effects. Two separate surveys conducted among members of the American Institute of Ultrasound in Medicine (AIUM) found that between 72 and 80 percent of end users, including doctors, could not locate the thermal indicators on their own machines; of those who could locate the thermal indicators, only a small percentage could correctly read them. While most babies do not appear to suffer any harm from routine scans, it is fair to say that if the majority of ultrasound users do not know how to take safety precautions, prenatal ultrasound cannot be regarded as reliably safe for all babies.

Respectfully submitted,

Caroline Rodgers

Eileen Nicole Simon

December 8, 2009

I will try to listen or view the webinar for this meeting. I would like the following comment considered: In addition to research, the IACC should identify dangerous invasive practices that have become part of standard perinatal care. Can these just be stopped? I have posted some of the evidence on my website, conradsimon.org, and will post more, about the gradual adoption of these interventions:

1. Prenatal use of any medications. The finding of minor physical anomalies is more likely due to prenatal exposure to drugs than any genetic predisposition.

2. Clamping of the umbilical cord immediately after birth. This prevents normal transfer of placental blood to the lungs to initiate breathing. Resuscitation equipment should be available on a cart that can be wheeled over to the delivery table. Ventilation can only work if the capillaries surrounding the alveoli are filled with blood (hemoglobin) to receive oxygen in exchange for carbon dioxide.

3. Vaccinations should not be given in the newborn nursery. In the past vaccines were not given until 6 months of age.

I will continue to attempt to get these issues discussed.

Eileen Nicole Simon, PhD (biochemistry), RN (Registered Nurse)

Note: Personally Identifiable Information (PII) has been redacted in this document

Theresa Wrangham

December 8, 2009

safe Minds
Sensible Action For Ending Mercury-Induced
Neurological Disorders

December 07, 2009 *****VIA EMAIL*****

Thomas Insel, MD
Chair, Interagency Autism Coordinating Committee
National Institute of Mental Health
6001 Executive Boulevard
Bethesda, MD 20892-9669

Re: Update of Strategic Plan for Autism Research

Dear Dr. Insel,

SafeMinds is taking this opportunity to additionally comment on the strategic planning process to date. While there are areas of improvement that we appreciate, such as including of a fuller understanding of the IOM 2004 report as it applies to the limitations of epidemiological studies to detect susceptible subpopulations, there are areas that require additional action that were noted during the initial strategic planning in 2008 as requiring attention and which remain unaddressed by this year's strategic planning process.

Lack of Environmental Expertise: Specifically, we are concerned by the lack of expertise during the updating of the strategic plan as it relates to toxins and environmental factors. SafeMinds has attended and/or participated in the scientific workshops as well as strategic planning process since the IACC's inception. We note that during the 2008 scientific workshops that IACC member and NIEHS representative Dr. Lawler was the only environmental representative to participate and there was no toxicological expertise present. This year there was no environmental/toxicological expertise present for discussions on causation and prevention (Question 3). The lack of environmental and toxicological expertise present during strategic planning was noted last year and again this year by SafeMinds to the committee and was also noted this year by the science community participating on panel three.

We are appreciative of the committee's recognition for the need of environmental citations and other environmental and epigenetic wordsmithing that Dr. Lawler will be adding to the plan. However, while very needed, these additions should not have fallen to a single IACC member to accomplish so late in the game. It is an area of the plan that SafeMinds and other autism organizations over the course of strategic planning have expressed as needing attention and improvement. Dr. Lawler cannot be reasonably expected to do justice to this section with the little time allotted to her and this section should have been given proper deliberation and consideration during science panels and throughout the course of the updating process that every section of the plan has been given. We feel this is another example of how the absence of environmental risk factor and toxicological expertise contributes to the underdevelopment of this portion of the plan. Now the committee will be asked to evaluate, and approve of, the new wording during its next meeting. This is simply not enough time.

There were also other comments made by IACC members during the committee meeting of October 23rd regarding additional areas that lacked the expertise necessary during the science panels to adequately address all aspects of the plan. This continued absence of expertise negatively impacts the strategic plan and creates a bias on the importance of genetics vs. environmental risk factor research.

REQUEST: Please clarify why this expertise continues to be absent, given that it is considered a promising area of research and was noted as lacking in 2008's strategic planning process. What measures will be taken overall to prevent these expertise deficits in the future? SafeMinds also requests that the committee consider the following objectives, which were submitted via the RFI process and which, due to the lack of expertise and review/integration of responses, were not considered by the committee. These items would assist in the much needed development of environmental risk factor research absent in the plan.

- Include environmental factor/toxic load screening in early detection.
- Use existing data from National Center for Environmental Health (NCEH) National Health and Nutrition Examination Survey (NHANES) to facilitate the establishment of reference ranges for unusually high exposure levels to a toxicant within individuals/groups, identify the proportion of the population with toxicity levels above those with known adverse health outcomes, tracking time trends in exposures to determine what changed in the environment and set priorities for research on the health effects of exposure to environmental chemicals.
- Conducting body burden studies on our children to investigate the toxic load of toxins like mercury and aluminum, their combined and isolated toxic synergistic effects in the presence of other toxins, as well as when present with viruses and bacterial infections.

Vaccine Safety Research: Following IACC statements in January regarding HRSA and HHS inherent conflicts of interest, there are process issues that remain unaddressed. Additionally, the IACC requested the expertise of the NVAC as it relates to autism vaccine objectives, yet autism specific findings from the NVAC's report are not adequately reflected in the strategic plan. These objectives must necessarily be adopted to comply with the charge as provided by the Combating Autism Act (CAA) and 1986 Mandate for Safer Childhood Vaccines, which requires research to reduce vaccine adverse events. Specifically vaccine related issues are:

- Integration and support of NVAC recommendations specific to autism. Previously removed vaccine objectives specifying animal and cell line models were also acknowledged by Dr. Lawler during the October 23rd meeting of the IACC as being the "bread and butter" of NIEHS and greatly valued. However, this objective was again removed from the strategic plan this year.
- Dr. Lawler acknowledged during the November 10th IACC meeting that using on-going studies prospectively would probably not yield the statistical power necessary to ascertain much needed baseline comparative information on vaccines.
- Ethics for retrospective comparative population study – Washington, Minnesota and Colorado are but a few states with high by-choice exemptors (5.7%, 6.8% and 4.7% respectively) that could be used for vax/alt-lite-unvax study with no ethical issues. Washington state has noted no differences within their philosophical exemptors that would prevent such a study. Homeschoolers, Amish and other populations are additional opportunities. This retrospective comparison would provide valuable baseline information on vaccines and total health outcomes. To date, we are unaware of any of the suggestions made at the joint IACC/NVAC meeting in this respect being pursued by the IACC to obtain this information as it applies to autism.
- Given HRSA/HHS conflicts of interest, vaccine objectives must be independent in oversight and conduct. Dr. Mark Noble from the University of Rochester presented on methods for achieving the necessary independent oversight and to date we are unaware of any response or action by the IACC to resolve these conflicts in an independent manner.

SafeMinds and many autism organizations feel strongly that the $16 million for vaccine safety objectives removed for a second time from the research agenda is but a fraction of the IACC budget. Indeed, this amount would only cover the lifetime care expenses of 12 autistic individuals. This small investment aligns with the intent of the CAA and is not an overemphasis on vaccine research, as is sometimes asserted by members of the IACC. This is particularly true when reviewing the budget recommendations of the IACC for genetic research, which is well funded privately and which received the lion's share of stimulus funds in Question 3 as opposed to funding the already acknowledged and underfunded environmental objectives within the plan.

REQUEST: To better accomplish goals within the strategic plan and integrate the findings of the NVAC as they relate to autism, and in compliance with the 1986 Mandate for Safer Childhood Vaccines and the intent of CAA, we request the following:

- Identification and analysis of studies, such as CHARGE, EARLI, SEED and NCS, regarding their ability to prospectively and reliably yield comparative health outcomes with recognized statistical power with medically verified vaccine records, etc. on vaccines. Where the ability to yield such information is deemed lacking in the previously mentioned studies, the IACC should develop recommendations and budget estimates to enhance protocols appropriately to assure good use of resources and proactive development in gathering this information.
- Clarification on exclusion of autism specific recommendations from NVAC report from the strategic plan, e.g. “What we know”, “What we need” “Research Opportunities” and research objectives.
- Integration of the autism specific recommendations made by the NVAC report.
- Clarification of independent oversight mechanism for newly adopted vaccine objectives to overcome acknowledged inherent conflicts of interest held by HRSA/HHS.
- Clarification of impediments to, and ethical considerations (often cited by IACC members) of, a retrospective comparative population study of vaccinated vs. unvaccinated as a means of gathering data on total health outcomes.

Process: We share the concerns expressed by IACC public members Ms. Redwood and Ms. Singer that not enough time is given for the updating process, particularly the committee’s time in reviewing and discussing the draft product. Lessons learned from 2008 planning were not applied to 2009 and for a second year additional special meetings had to be called to complete the strategic plan. Below are specific deficits of the process to date:

- This year’s strategic planning process is absent of a mechanism for meaningful review and integration of RFI comments into plan, whereas last year many suggestions were incorporated into the draft plan for the committee’s consideration.
- There are possible FACA violations due to the absence of draft and meeting materials not made available to the public for use during meetings. Additionally, public comment for those listening on the phone during meetings is restricted.
- The committee doesn’t respond to questions and requests submitted to the committee, further marginalizing meaningful public participation.
- Science panels did not have funding cycle information or progress reports for ongoing studies as they apply to the strategic plan. This lack of information negatively impacted the panel’s ability to assess progress of the strategic plan

and determine a starting point in updating the plan and noted the need for this information to properly and efficiently make recommendations to the IACC.

- **Mission/Vision/Introduction:** There was no direction during the RFI process on how to submit comments on this portion of the plan. Additionally these strategic planning statements are absent of NIH values on causation, recovery and prevention. Cross-cutting themes are also absent of recovery statements.
- The updating process, in general, lacks sufficient time for going through the edits, reasonable deadlines for committee members and science panelists to submit edits for final review and discussion during full committee meeting – everything is too rushed at the end.

REQUEST: Please clarify why information necessary for updating of the strategic plan was not available to the science panels and what mechanism will be used to prevent this planning deficit in the future. We request that adequate time be given to the entire process, as did IACC members, and would like clarification on the role of the strategic planning subcommittee in this sense and how the overall process will be improved in the next update of the strategic plan. We also request greater meaningful public participation measures be identified by the committee, such as clarification of what prevents public comment from phone participants when other entities such as the IOM allow for oral public comment by those on the phone; draft/meeting materials be made available to the public on the same basis that they are made available to the committee/panels; a mechanism for committee response to consistent requests made by the public and a review mechanism for public responses to RFI as they apply to strategic planning for integration into the strategic plan.

The latter could be accomplished via an advisory panel or panels similar to those used by the Department of Defense CDMRP model for autism research. These have been requested to be considered by the committee and recommended to the Secretary to enable a higher degree of meaningful public participation, as well as assist in the strategic planning process. Please clarify why these requests have not been identified as agenda items for the committee’s consideration. Given the continuation of previously identified strategic planning deficits, what measures are being implemented to achieve more meaningful public participation and efficient strategic planning in the absence of advisory boards and panels previously suggested?

Lastly, ASD "is" a national health emergency, not an "emerging" emergency and the plan does not currently reflect the necessary urgency commiserate with the continued growth of ASD. Please clarify why with the recent reports of increased prevalence autism remains an “emerging” emergency and why no time has been set aside to update the mission, vision and cross-cutting themes section of the plan.

In closing, we are appreciative of the time committee members give to this process. However, the strategic planning subcommittee appears to have been under-utilized and their scope ill-defined during this year’s process. Many of the deficits noted here have been noted prior to this year’s updating process and have been previously submitted with no response forthcoming from you or the committee. Thus, the courtesy of your response, as well as a response from the committee, specifically addressing the concerns above is formally requested. Responses should be sent directly to me at [PII redacted]. Additionally, please consider this our public comment for the IACC meeting to be held on December 11, 2009.

Sincerely,

/Theresa K. Wrangham/
Theresa K. Wrangham,
President

Note: Personally Identifiable Information (PII) has been redacted in this document

Phoebe Tucker

December 9, 2009

Subject: I would like to be a part of your discussion

I am a Speech/Language Pathologist and Augmentative/Alternative Communication Specialist who has opened a center for autism with sensory integration rooms, virtual reality (VR), and an extensive library of software and voice output devices. I opened this through United Cerebral Palsy – a nonprofit organization - to help as many individuals with ASD as possible. GO to my website www.montanoatcenter.org

Me and my staff are recording results of individuals with “classic autism” – those who are essentially non-verbal with specialized technology such as when the person speaks a sound they create an entire scene on the wall with their voice. We use virtual reality to create language stimulating environments.

By placing your foot or hand within a designated area fish swim around it and when you move you hear the movement of water. Miami Children’s Hospital flew up to see us because we are the only center in the country using VR as a remediation tool. We have reading software for our higher functioning (non-Asperger’s) individuals. We have social groups with a technological twist that helps our clients recall social stories and strategies.

I would like to be a part of your meeting. I have an evaluation from 9 to 11 – but would call in after that. Please call so I can discuss this further [PII redacted] in Bridgeport, Connecticut.

Phoebe Tucker MS CCC/SLP (Master of Science, Certificate of Clinical Competency-Speech-Language Pathology)
AAC (augmentative and alternative communication) and Director of the Montano Assistive Technology Center

Note: Personally Identifiable Information (PII) has been redacted in this document

Phillip Baker

December 10, 2009

Subject: Lyme borreliosis-induced Autism

A hypothesis was recently published by Bransfield et al. on the association between Lyme borreliosis and autism spectrum disorders (see attached) of which I am very skeptical. Do you know of any peer- reviewed publications that support -- or refute-- such a claim? The reason I ask is that I am getting many e-mail messages from distraught parents with autistic children who feel this may be a hopeful approach in treating autism. I would like to be able to tell them -- in all due conscience-- that there is no foundation for such a view.

Sincerely,

Phillip J. Baker, Ph.D. Executive Director
American Lyme Disease Foundation Lyme, Connecticut
[PII redacted]

Note: Personally Identifiable Information (PII) has been redacted in this document

Antamica Grimes

December 10, 2009

Subject: ASD

Hello, My name is Antamica Grimes. My 8 year old daughter has been diagnosed with "characteristics of autism". She was diagnosed with a developmental delay at 9 months old. I noticed that at 4 months she could not hold herself up like my other kids did at 4 months and addressed these concerns with her doctor who let me know that all kids do things in different time.

However at 9 months when she still could not, I took her to another doctor who diagnosed her with a developmental delay and she started receiving physical, occupational, and speech therapies. She is still far behind, though she has made in my opinion tremendous progress, she is in special education (2ND grade) but performing at a less than kindergarten level. I have moved to Temple, Texas and I want to know if there are any free or with nominal fee services here that I can get to help her? I am employed and a single mother of four. My income is the only income in the home as I do not receive SSI (Social Security Insurance), child support, or any other federal or state government aid. I really want her to progress and though I think the school system is great, I also feel that there is a lot more help that she could be receiving in order to "heighten" her progress. My home number is [PII redacted] and my email address is [PII redacted]. If you would, please send me any info you have on helping her.