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Autonomously Autistic: Exposing the Locus of Autistic Pathology

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Abstract

The locus of pathology exists not in the autistic person, but in the interaction between a hostile environment and the subjugated autistic. It is essential for parents, practitioners, educators, and autistic people themselves to ask the crucial question— Is the autistic a machine, or an organism? Are we active agents in our own embodied experience, or are we a locus of behavior? It is not with defiance, but autonomy, that I declare as an autistic person— I am not a manifestation of stimuli and response. I am agential. I am Autonomously Autistic.

Keywords

autism, autonomy, agency, rights, behavior, barriers, self determination

Introduction

“... Disability is a natural part of the human experience and in no way diminishes the right of individuals to— (A) live independently; (B) enjoy self-determination; (C) make choices; (D) contribute to society; (E) pursue meaningful careers; and (F) enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society” — Rehabilitation Act 1973

This excerpt from the Rehabilitation Act outlines a number of rights, presumably rights that are enjoyed unfettered by other citizens of the United States, but which must be supported by additional protections for people with disabilities given the barriers, both structural and societal, that exist in our present culture. Though not directly related to the term “self-determination” as used in law, I will examine the Self-Determination Theory (SDT) of human psychological needs, motivation, and self-actualization (Deci & Ryan, 1985), and evaluate how current interventions for autism serve to erode autistic people’s autonomy and self-determination. Despite the field of Disability Studies’ rhetorical progress toward new models of disability, Autistic subjectivity is still locked within medical pathologies and assumptions of deficit. Self-Determination Theory provides

an intriguing contrast to other psychological frameworks, making it possible to reconceptualize and re-localize deficit. We can then disrupt our assumptions and form new principles that empower autistic people to develop in autonomous, competent, connected, and self-directed ways.

To do this, we must first understand what self-determination in the Rehabilitation Act means, what Self-Determination Theory is, and what the implications of self-determination are in a disability context. We must also evaluate what environmental and societal factors support vs. erode self-determination in the individual, and what this means for behavioral interventions that follow from a mechanistic, behavioristic framework of human psychology, rather than the organismic framework defined by Self-Determination Theory. From this investigation, I propose that the locus of pathology exists not in the autistic person, but in the interaction between a hostile environment and the subjugated autistic. It is essential for parents, practitioners, educators, and autistic people themselves to ask the crucial question— Is the autistic a machine, or an organism? Are we active agents in our own embodied experience, or are we a locus of behavior? It is not with defiance, but autonomy, that I declare as an autistic person— I am not a manifestation of stimuli and response. I am agential. I am Autonomously Autistic.

Self-Determination in The Rehabilitation Act of 1973

There are three occurrences of “self-determination” in The Rehabilitation Act of 1973 relevant to people with disabilities. In no instance is the term explicitly defined, but based on context of the surrounding material, it is reasonable to infer the intention was that self-determination is related to “independent living” (p. 3), “choices” (p. 3), “respect for individual dignity” (p. 5), and “empowerment” (p. 162). Merriam-Webster defines self-determination as “free choice of one's own acts or states without external compulsion.” It will become clear in the next sections that the concept of self-determination as presented in The Rehabilitation Act is consistent

with Self-Determination Theory, and that behavioral intervention is incompatible with empowering self-determination in young disabled children.

Self-Determination Theory

Edward Deci and Richard Ryan’s Self-Determination Theory (SDT) posits that all humans possess innate needs for autonomy, competence, and relatedness. Optimal well-being results when a person is supported and empowered by healthy relationships to develop an integrated self through autonomous, intrinsically motivated goal setting and striving (Ryan & Deci, 1985). The concepts encapsulated within SDT emerged from early investigations into the impacts of external mediators of behavior on human motivation. In essence, these were investigations into the conflict between extrinsic and intrinsic motivation (Deci, 1971, 1972a, 1972b, 1976, and more). From these investigations, the Cognitive Evaluation Theory—concerned with the effects of external conditions, demands, and expectations on internal processes of understanding, evaluating, accepting or rejecting—precipitated the implications of how we exercise power and control, and its impacts on the psyche of those around us (Ryan, 1982, 1983, 1984).

As it turns out, our cultural tradition of merit-based reinforcement, or rewards and punishments, are inherently subjective to the moral evaluations of the rewarder, and effective only as a means of control downward along power gradations (Ryan, 1982; Deci & Ryan, 1987). Such behavioristic frames of control are empirically contraindicated in the development of intrinsic motivation, integrated self-regulation, and autonomy (Deci, Koestner, & Ryan, 1999a). These conceptualizations of human motivation as a multi-faceted constellation of processes that are not additive but antagonistic, upend popular convictions of how we effectively relate to the people in our lives that we are meant to foster, educate, empower, and support.

Self-Determination Theory positions itself as directly and unapologetically antithetical to behaviorism, a fact that manifests in the literature repeatedly in behaviorist commentary on Deci and Ryan's research with subsequent responses (Ryan, 1996; Deci, 1999a-b). Deci sees this conflict as almost amusing. He proposes that the mechanistic, or behavioristic view of human psychology follows from a different set of assumptions than organismic views of the self, and thus it is natural that the two paradigms are incompatible with each other (Deci, 1976, ch. 1). He goes further, illustrating that among many branches of psychology, behaviorism stands alone in its mechanistic view of human behavior:

"Humanistic psychologists, like cognitive theorists, believe that humans are active organisms making continual choices about what to do. Unlike cognitive theorists, however, humanists have been less concerned with thought processes and more concerned with the 'wholeness of a person,' that is, the inner force and phenomenological experience of people. Still other psychologists have concentrated on the affective component of behavior, postulating that people develop patterns of behavior and hierarchies of responses as a result of the affect associated with their behaviors. Finally, behaviorists are concerned with the mechanistic associative links which develop between stimuli and responses through reinforcement of a response in the presence of a stimulus." Deci, 1976 from *Some Comments on the "Why" of Behavior in Intrinsic Motivation in Intrinsic Motivation*

Metatheoretical differences aside, it is crucial to recognize that Self-Determination Theory is not built solely on its theoretical assumptions. Over the past 30 years, it has been continuously refined and reframed by a robust series of studies and field observations. Deci, Ryan, and their colleagues have investigated not only the relationship between extrinsic motivators and intrinsic motivations (Deci, 1971, 1972a, 1972b, 1976), but also the relationship between the superior and the subordinate (Deci, 1981; Ryan, 1982; Deci & Ryan, 1987), the subordinate and the self (Deci & Ryan, 1983, 1985, 1995; Ryan, 1989, 1997), as well as the subordinate and the family (Ryan, 1995; Grusec, 1997; Guardia et. al. 2007). The evidence is clear: extrinsic motivation erodes intrinsic motivation (Deci, Koestner, & Ryan, 1999a); controlling behaviors by the superior have

negative productivity, efficacy, and emotional impacts on the subordinate (Deci, 1972, 1981); and, most importantly, that there are alternatives to control— namely informational feedback, allowance of choice, and authentic connection— that there are definable, concrete means of fostering competence, empowering autonomy, and creating relatedness in the people under your care (Ryan & Deci, 2017).

Despite heavy behaviorist occupation of the Special Education domain, Deci and Ryan, as well as their colleague Grolnick, were not shy about implicating behaviorism when analyzing their findings from investigations into the efficacy of SDT within children with various learning disabilities (Deci, 1986).

“...Autonomy support has generally been associated with more intrinsic motivation, greater interest, less pressure and tension, more creativity, more cognitive flexibility, better conceptual learning, a more positive emotional tone, higher self-esteem, more trust, greater persistence of behavior change, and better physical and psychological health than has control.” (Deci, 1987)

Prior to their work in this field, Self-Determination Theory gained concepts of motivational orientations. These orientation measures found that people tend to be oriented within a coordinate space between autonomous motivation, controlled motivation, and impersonal motivation.

“...the autonomy orientation is the embodiment of self-determination in personality, for it entails choices based upon information. Thus, a high level of this orientation would lead to self-determined functioning. The control orientation does not support self-determination, for although one can have control over the attainment of outcomes, and therefore can be intentional, one’s behavior is perceived to be initiated and regulated by those outcomes (i.e., by controlling events) rather than by one’s own choices.... Impersonal causality represents the antithesis of self-determination, for the person has no experience of being able to attain needed outcomes, let alone being the initiator of goal-directed behavior. Thus, a high level of the impersonal orientation would lead to the least self-determined functioning.” (Deci & Ryan, 1985, p.114)

Though no one truly exists at the apex of any one orientation, it is illustrative to describe the archetype of each orientation. Someone who possesses a fully autonomous motivational

orientation has a fully integrated sense of their needs, values, desires, and goals, and perceive within themselves a genuine competency and embodied capacity for achieving. Contrarily, a fully controlled motivational orientation describes someone with an introjected set of values and goals, and are driven by the demands, expectations, and 'shoulds' imposed by others. They spend much of their cognitive effort avoiding aversive states, to the point where even their reward seeking is driven by an avoidance of the absence of reward. Finally, the impersonal motivational orientation is symptomatic of someone who perceives no order or logic in how their behavior is regarded by their caregivers or peers. They have been dispossessed of all embodied competency.

In studies of school-age children with learning disabilities, Grolnick & Ryan (1990) found that perceived competency in the classroom might have a causal relationship to motivational orientations, with repeated failures engendering a lack of personal control over performance, pushing them into the impersonal motivational orientation domain. In 1992, Deci et. al. found no significant relationship between performance on IQ measures and motivationally relevant variables. This finding undermines assertions made by many behaviorists that children with developmental disabilities possess no innate motivational mechanisms and thus operant conditioning is necessary to educate (read: train) them. This same study also found competence to be a significant psychological factor for children labeled "learning disabled" (as reflected in Grolnick & Ryan, 1990), whereas children labeled "emotionally handicapped" were most significantly impacted by autonomy factors. It is no surprise that children under this label, presumably 'emotional' in 'aberrant' ways, would find themselves chronically controlled, their natural ways of feeling and being constantly disciplined and suppressed, their autonomy infringed upon and their powers of self-determination rendered inert.

It is important not to confuse the presence of impersonal or controlled motivational orientations with an innate trait in the individual that predisposes them to these orientations. That a child is already within a controlled motivational orientation is not a justification to use behavioristic paradigms of rewards and punishments to motivate that child. Our expression of traits, including our motivational orientations, have been found to fluctuate in the presence of different relationships (Sheldon, 1997; Guardia, 2000; Guardia & Ryan, 2007). In other words, change the environment, change the orientation. It does not follow that a person’s present position within the coordinate space of orientations is innate and permanent. What does follow is our responsibility as caregivers to support, empower, and provide for those in our care to move with competence and dignity towards autonomy. Disability is not the lack of intrinsic motivations for autonomy, competence, and relatedness— it is what happens when the environment assumes a particular way of supporting these needs that is not, in fact, universal. The needs are universal. The means of support are not.

In his 1987 piece, “The Role of Motivation in the Future of the LD Field”, Deci makes his position clear:

“Having specific behaviors reinforced is certainly not the greatest need for most (or perhaps any) LD children; what they do need is a set of conditions that will help them grow and develop. ... People's self-determination is threatened by events or contexts that control them, in other words, that pressure them to behave in specific ways. ... The nature of the human being is to experiment, explore, grow, and develop. Its nature is to strive for effective interactions with the environment, to move from dependence toward autonomy, and to construct an ever more elaborate, refined, and unified internal representation of itself in relation to the world.” (p. 598)

Early Intensive Behavioral Intervention

“Have your child work for what he wants; make him responsible. Developmentally disabled persons have to work particularly hard. Their work is to learn, your job is

to teach. The responsibility is shared. With responsibility, the developmentally disabled individual takes on dignity and 'acquires' certain basic rights as a person. No one has the right to be taken care of, no matter how r***** he is. So, put your child to work; his work is to learn." (Lovaas, 1981)

From this one quote, we can begin to build notions of what Ivar Lovaas's meta-theoretical assumptions were when developing his Early Intensive Behavioral Intervention (EIBI) protocol for the treatment of autism. Some clarification of terms will be necessary in order to understand the relationships between behavioral interventions in general and EIBI in specific. Public understanding of Applied Behavioral Analysis (ABA) is often entangled with clinical experiences in general, and autism 'treatment' in specific. There are researcher uses of ABA that are not related to autism or any other disability (usually in animal behavior labs), as well as uses of ABA in practice that are not as procedurally rigorous (usually using the label in order to pass as coverable by insurance). In order to maintain a clarity of purpose and perspective, here ABA will refer to the use of operant conditioning (in which the desired behavior or increasingly closer approximations to it are followed by a reinforcing stimulus) individualized for the participant based upon analysis of observable behavior to make changes to behaviors that have been designated by the practitioner as abnormal or harmful.

Operant Conditioning is the mechanism at work within ABA, which is the procedure employed by EIBI, which in turn is a protocol which is employed over extended daily hours for months or years, with the goal of extinguishing autistic traits in preschool age children such as echolalia, motor stereotypies, and sensory seeking/avoidant behavior, with the assumption that this extinguishment produces a child that can be placed in mainstream school. It is also used to drill the component motions of speech, dressing, and toileting, with the assumption that these communication and self-care skills cannot be internalized any other way.

Ivar Lovaas developed EIBI over the course of many years, beginning in the early 60s with investigations into the procedures for producing imitation in autistic (sometimes labeled as schizophrenic) children (Lovaas, 1964, 1965, 1966a, 1966b, 1967). During these studies, he began to notice the sensory processing idiosyncrasies of autistic children (Lovaas, 1971a, 1971b, 1971c, 1973; Reynolds, 1974). Understanding how autistic children’s sensory systems differ from non-autistic children would be the natural precursor to developing a behavioral intervention given that operant conditioning is dependent upon predictable stimulus-response bonds. By the time Lovaas published “Teaching Developmentally Disabled Children: The ME Book” in 1981, Lovaas had solidified his concepts of how to most effectively and efficiently teach the autistic child based on only a handful of individual case studies (his studies generally involved only 2 subjects, sometimes as many as 6). It is important to note that these techniques were also used in a case study entitled “Behavioral treatment of deviant sex-role behaviors in a male child” (Rekers & Lovaas, 1974). EIBI is the root of conversion therapy— rather than extinguishing ‘gender deviancy’, EIBI for autism seeks to extinguish ‘neurological deviancy.’

“You see, you start pretty much from scratch when you work with an autistic child. You have a person in the physical sense— they have hair, a nose and a mouth— but they are not people in the psychological sense. One way to look at the job of helping autistic kids is to see it as a matter of constructing a person. You have the raw materials, but you have to build the person.” Ivar Lovaas as interviewed in *Psychology Today*, 1974

In 1987, the UCLA Young Autism Project results were published. This study, found that 47% of participants in the intervention group became “indistinguishable from their normal friends” (Lovaas, 1987, p. 8). One might ask how this ‘success’ rate differs from random chance. The experimental group consisted primarily of children whose parents insisted on the intervention, while the control group was predominantly assigned based on institutional and socioeconomic

factors (p. 4). It would seem plain that the most significant influencer of the participants’ success was simply whether they were in a position to be mainstreamed at all. This and other methodological concerns were broached by Schoper et. al. (1989), Gresham and MacMillan (1998), Howlin (2009), and others. Lovaas would endeavor to address those concerns in replication studies published in 1998 (Lovaas) and 2008 (Reichow). However, that the results were replicable doesn't really mean much when it's the underlying assumptions, goals, and criteria for success that we take issue with.

Earlier, we discussed the root assumption of behaviorism— that of the mechanistic view of human behavior as an observable and predictable collection of stimuli-response bonds. It would be unfair to say that behaviorists do not believe in internal processes or the self (excepting Skinner of course), but the internal states are more or less irrelevant to the rigidity of their observational and applied process of operant conditioning. Lovaas was not a devout Skinnerian at any rate. He believed in the self as much as he believed that the autistic did not possess one. He viewed the presence of autistic traits as the absence of personhood. The autistic body was a homunculus into which a soul had to be poured— repetition by repetition, morsel by morsel, extinguishment by extinguishment, shock by shock. Touch nose. Good little pidgie.

Whenever criticized for these techniques, Lovaas would expose his particular brand of benevolent cruelty: “While the use of electric shock on individuals with intellectual delays issues may seem inhumane or archaic, its effectiveness in changing behavior could not be disputed.” (from The Lovaas Center Website.) Despite his bravado, Lovaas seemed particularly self-conscious of these critiques. His replication studies seem less interested in validating the method than in validating the method in the absence of explicit aversive punishments. It is not uncommon

to find a passage in any particular piece lamenting how inconvenient it is that autistic children are 'simply not reachable any other way.'

"The showing of love and acceptance, the holding, the efforts to arrange a situation in which children will speak, and the physical exercises are all examples of attempts at stimulus control.... Stimulus control can only change behavior if there is already behavior to control, and this does not seem to be the case for autistic children."
(Lovaas, 1989, p. 25)

In other words, 'Loving them is nice and all, but it won't make them people.'

Some may take issue with my use of Lovaas's work here. Those within the contemporary ABA community of researchers, practitioners, and parents would like to distance themselves from a history of violence. It is common to hear rebuttals to ABA critiques like, "ABA isn't like that anymore," "ABA is gentle now," or "Physical aversives are no longer legal," (access Sequenzia, 2011). Such appeals to 'moving forward' fail to recognize that Lovaas does not begin and end with the Young Autism Project from 1987. As the publications dates indicate, Lovaas remained a prominent researcher and author in the field for nearly 40 years. His final book, "Teaching Individuals with Developmental Delays: Basic Intervention Techniques", has been cited over 560 times since being published in 2003. From biographic features (Özerk et. al. 2016) to obituaries (Koegel, 2011), behaviorists venerate, revere, and adore Lovaas. There is no way to separate Lovaas's work from ABA literature writ large, just as there is no way to separate Lovaas's opinions of autistic children from his work. Lovaas even seems to have prepared the field for a defense against SDT, "It is unfortunate that this alternate path to teaching [by optimizing the child's motivational system] is not open to us since we do not know how to establish conditioned reinforcers or to build motivation in autistic children." (Lovaas, 1974, p. 121) It is unclear why Lovaas and other behaviorists are so certain that autistic children cannot be motivated to learn in

more natural ways, though I suspect much of these assertions about autistic children follow from the nature of EIBI's teaching goals.

As has been noted before, the driving goal of EIBI/ABA is to produce a child that is 'indistinguishable' from a 'normal' child. Very few programs, if any, claim that they can cure or eliminate autism. But they do claim to reduce 'symptoms', and eliminate 'behaviors'. It is assumed, when a child is only 2 or 3 years old, that the presence of autistic traits is incompatible with education. It is assumed that the autistic child at 3 will be the autistic child at 5 if no intervention is employed. With programming that is scheduled in-step with a full-time job, 40 hours a week for 'as long as it takes,' how can anyone separate the effects of the protocol from the natural development of a child? If, "the spontaneous use of language occurred about eight months into treatment" (Lovaas, 1973, p. 131), what does that even mean? Who doesn't have stories of a family member who didn't speak a word until 4 years old, suddenly bursting with complete sentences? I have two such stories in my own family. One of them is autistic, and the other isn't. Neither of them had EIBI.

Graduation criteria and outcome comparison studies reveal yet another facet of the dubious nature of EIBI's evidence base. The practitioners both define, construct, and then satisfy the criteria for success. If I define flapping as aberrant, and I withhold your favorite toy unless you maintain 'quiet hands', and you comply, then I have 'successfully' eliminated 'aberrant behaviors'. A circular logic— The snake eats its own tail. In a 2007 comparison study by Eikeseth, long-term follow up of children who had been participants in ABA were compared to children labeled as having an "eclectic" treatment regimen. The criteria for who had 'better outcomes'? The presence of fewer "aberrant behaviors" (p.273). There was no acknowledgement that the goals of these

“eclectic” treatments did not target “aberrant behaviors”. No consideration was given to the emotional and mental health of the children or the families.

This willful ignorance of the emotional impacts of ABA on children is the core of the Autistic Community’s rejection of behaviorism. Personal testimonies (AutisticsAgainstABA, 2017; Bascom, 2012), disability scholarship (Kupferstein, 2018; Broderick, 2011; Dawson, 2004), and social media campaigns (BetterWaysThanABA, 2017), all attest to the traumatic impact ABA has had on autistic psyche. However, very few studies have focused on the stress responses and emotional health of autistic children, and instead focus on the mental health of the parents (Stewart, 2016). It seems there is another assumption at work here, that the emotional health of autistic children can’t be assessed by standard measures. Yet Deci and Ryan assessed hundreds of disabled children with success, many of whom were probably autistic. Shae et. al. (2013) specifically investigated motivational orientations in autistic students and found that those who perceived high autonomy support from their teachers reported greater degrees of self-determination and competence.

Probably the most damning evidence against the efficacy of EIBI for autism boils in the ‘avalanche’ of autistic adults just now receiving their diagnosis (Brugha, 2011). Often considered to have ‘masked’ their traits or ‘passed’ for neurotypical, it is usually assumed that diagnosis was missed in childhood because they were ‘too high functioning’ to be noticed. But if we consider the state of autism diagnosis and its very brief history, it seems more likely that people in their 30s, 40s, and 50s simply didn’t have access to practitioners competent in autism diagnosis. Evaluations of elderly populations in care homes, many of whom have been institutionalized for most of their lives, are revealing ‘missed’ autistics there as well (Wright, 2015). If anything, the survival of

unrecognized autistics into adulthood tells us that Lovaas's 47% success rate may be random after all.

The Future is Autonomous: Setting Autistics Free

"If you have an organism and you have complete control over that organism's environment, you can, with rewards and punishments, get that organism to do—almost anything. ...The problem is ... the reality of the cage. Which is most of us are not in a cage in the same way. We might be controlled by rewards and punishments, or the contingencies that someone puts us under, but if we really don't like it or it becomes particularly aversive, at least for most of us, we can leave the cage."

Richard Ryan Opening Remarks from the 5th Conference on Self-Determination Theory 2013

The way we treat other people says a lot about our assumptions of their nature. The way we treat disabled people, both in the general and the clinical domain, brands them with those assumptions. Our implicit biases feed into our theoretical machinations, inform our research goals, guide our treatment protocols, infest our education, and manifest in our culture. The snake eats its own tail. It is my hope that I have challenged you to investigate and evaluate the assumptions that drive your perceptions of what is deficit, deviant, and disordered in the autistic.

Deci and Ryan's findings of a suppressed competence and autonomy in disabled children and the relationships between these suppressions and motivational orientations may tell you a different story depending on what your assumptions about autistic people turn out to be. If you believe, as I do, that human beings possess innate needs for secure connection, competent embodiment, and liberated autonomy, then it should follow that suppression of these characteristics in the autistic individual originates not from within, but from the intensity and unpredictability of surrounding environment. It is unnerving that Lovaas himself seemed to detect the same concept, stating that "their problems can be viewed as a mismatch between their nervous

system and the environment, solved by manipulating the environment” (Lovaas, 1989, p. 22). It is a horror that he chose to manipulate the environment to his own ends—extinguishing our autistic expression, building compliance through coercion—rather than respecting the self-determination of the children in his care.

As Ryan stated, most of us can “leave the cage.” Behaviorism often fails more obviously when it is applied to able body-minded adults (Kohn, 2010). We have to ask why this cage is acceptable for autistic children when we would never consent to be in it ourselves. If there is any doubt about the efficacy of EIBI; if we are skeptical of ABA practitioners’ goals for ‘indistinguishability’; if we believe that autistic children are agential organismic beings with the right to connection, competence, autonomy, integrated self-regulation and self-determination; if we know that operant conditioning and contingent reinforcement erode autonomous motivation and interrupt the development of a competent embodiment and integrated true self—then why are we doing it?

Appendix A: Glossary of Terms

For simplicity and generalizability, all terms sourced from Merriam-Webster at merriam-webster.com unless otherwise cited.

agential: acting as an agent or with agency, as in causing intentional effects on the surrounding environment (personal definition).

antecedent: *a preceding event, condition, or cause.* In behaviorism, this is the stimulus, intentional or accidental/environmental, that precedes, and is assumed to have elicited, the following response.

Applied Behavioral Analysis (ABA): *the use of operant conditioning individualized based upon objective analysis of observable behavior to make changes to socially significant behaviors that are abnormal or harmful.* This paper asserts that the analysis cannot be objective when “abnormal or harmful” are defined by non-autistic observers making assumptions about the nature and function of autistic motion.

autonomous: *developing, operating, behaving, and being in an intentional, active, agential manner that is congruent with the integrated needs, values, and desires of the self (Ryan, 1997).* Autonomous does not mean independent *per se*, but allows for an intentional, consensual, deliberate dependency, as in any healthy personal or professional relationship.

aversive: *a noxious or punishing stimulus that elicits an avoidant response.* Even rewards can be aversive when you are forced to choose between comfort and compliance. One can be coerced into avoiding their natural motions in order to spare themselves the pain of being denied a reward.

behaviorism/istic/ist: *a school of psychology that takes the objective evidence of behavior (such as measured responses to stimuli) as the only concern of its research and the only basis of its theory without reference to conscious experience.*

competence: the experience of being in full control of one’s physical and mental capacities relevant to a task, of feeling consciously and adequately embodied in the performance of goals (personal definition).

contingent: *dependent on or conditioned by something else.* In behavioristic protocols, rewards or punishments are contingent upon compliance with practitioner demands.

Early Intensive Behavioral Intervention (EIBI): Specifically the protocol developed by Lovaas employed in his Young Autism Project. Broadly, the use of ABA in preschool-age children, over extended daily hours over months or years, with the goal of extinguishing autistic traits such as echolalia, motor stereotypies, and sensory

seeking/avoidant behavior, with the assumption that this extinguishment produces a child that can be placed in mainstream school. It is also used to drill the component motions of speech, dressing, and toileting, with the assumption that these communication and self-care skills cannot be internalized any other way (personal definition).

mechanistic: *behaviorist view of human behavior as the manifestation of environmental stimulus > subject response pairs (Deci, 1976).*

motivation: the rationale for acting, being motivated, compelled, or impelled to act in order to meet needs, demands, values, or desires.

autonomous: motivation to act based on fully integrated needs, values, and desires that are congruent with the self.

controlled: motivation to act based on externally enforced or introjected demands. Accompanied by a sense of coercion or aversiveness.

impersonal: motivation to act conflicted by beliefs that attaining goals are subject to chance or fate or are otherwise outside of their personal control.

intrinsic: motivation to act based on innate or internal thoughts. It is possible to have intrinsic controlled motivation, as in "keeping up appearances"

extrinsic: motivation to act based on external promises or demands. Rewards and Punishments. It is possible to have autonomous extrinsic motivation, as in choosing to compete (personally defined based on readings of Deci & Ryan).

operant conditioning: *conditioning in which the desired behavior or increasingly closer approximations to it are followed by a rewarding or reinforcing stimulus.* The underlying mechanism in ABA/EIBI.

organismic: *humanist/social/cognitive psychologist view of human behavior as the self-directed, agential, intentional action upon the surrounding environment. Based on the assumption that human beings are negentropic, or constantly striving toward the development and integration of greater complexity into the self (Deci, 1976)*

reinforcer: *a stimulus (such as a reward or the removal of an electric shock) that increases the probability of a desired response in operant conditioning by being applied or effected following the desired response.* More generally, an environmental condition that is pleasing or securing to the individual that promotes continued compliance to the contingencies of that condition.

response: *the activity or inhibition of previous activity of an organism or any of its parts*

resulting from stimulation. Compliance or defiance to the contingencies of the stimulus.

self-determination: *free choice of one's own acts or states without external compulsion*

Self-Determination Theory: all humans possess the innate needs for autonomy, competence, and relatedness. Optimal well-being results when a person is supported and empowered by healthy relationships to develop an integrated self through autonomous, intrinsically motivated goal setting and striving (Ryan & Deci 2017). This theory remains sound and backed by empirical evidence across cultures (Ryan & Deci, 2001) and abilities (Grolnick & Ryan, 1990).

stimulus: *an agent (such as an environmental change) that directly influences the activity of a living organism or one of its parts.* Rewards and Punishments, including verbal praise and the withholding of affection.

References

- Autistics Against ABA. (2017). *The Autistic Community Does Not Support Applied Behavioral Analysis in ABA Controversy Autism Discussion*. Retrieved December 05, 2017, from <http://abacontroversyautism.wordpress.com/2017/06/27/aba-autism-discussion/>
- Bascom, J. (Ed.). (2012). *Loud hands: autistic people, speaking*. Washington, DC: Autistic Press.
- Better Ways than ABA. (2017). Retrieved December 2, 2017, from <http://www.facebook.com/Better-Ways-Than-ABA-1853865171523852/>
- Broderick, A. A. (2011). Autism as Rhetoric: Exploring Watershed Rhetorical Moments in Applied Behavior Analysis Discourse. *Disability Studies Quarterly*, 31(3). doi:10.18061/dsq.v31i3.1674
- Brugha, T. S., McManus, S., Bankart, J., Scott, F., Purdon, S., Smith, J., ... & Meltzer, H. (2011). Epidemiology of autism spectrum disorders in adults in the community in England. *Archives of general psychiatry*, 68(5), 459-465.
- Dawson, M. (2004). Misbehavior of Behaviorists. Retrieved December 02, 2017, from http://www.sentex.net/~nexus23/naa_aba.html
- Deci, E. L., & Cascio, W. F. (1972a). Changes in Intrinsic Motivation as a Function of Negative Feedback and Threats.
- Deci, E. L., Hodges, R., Pierson, L., & Tomassone, J. (1992, 08). Autonomy and Competence as Motivational Factors in Students with Learning Disabilities and Emotional Handicaps. *Journal of Learning Disabilities*, 25(7), 457-471. doi:10.1177/002221949202500706
- Deci, E. L., Nezlek, J., & Sheinman, L. (1981). Characteristics of the rewarder and intrinsic motivation of the rewardee. *Journal of Personality and Social Psychology*, 40(1), 1-10. doi:10.1037//0022-3514.40.1.1
- Deci, E. L. (1971). Effects of externally mediated rewards on intrinsic motivation. *Journal of Personality and Social Psychology*, 18(1), 105-115. doi:10.1037/h0030644
- Deci, E. L. (1972b). Intrinsic motivation, extrinsic reinforcement, and inequity. *Journal of Personality and Social Psychology*, 22(1), 113-120. doi:10.1037/h0032355
- Deci, E. L. (1976). *Some Comments on the "Why" of Behavior in Intrinsic Motivation* in *Intrinsic motivation*. Plenum Press.
- Deci, E. L., & Ryan, R. M. (1985, 06). The general causality orientations scale: Self-determination in personality. *Journal of Research in Personality*, 19(2), 109-134. doi:10.1016/0092-6566(85)90023-6

- Deci, E. L., Koestner, R., & Ryan, R. M. (1999a). A meta-analytic review of experiments examining the effects of extrinsic rewards on intrinsic motivation. *Psychological Bulletin*, 125(6), 627-668. doi:10.1037//0033-2909.125.6.627
- Deci, E. L., & Ryan, R. M. (1987). The support of autonomy and the control of behavior. *Journal of Personality and Social Psychology*, 53(6), 1024-1037. doi:10.1037/0022-3514.53.6.1024
- Deci, E. L., Koestner, R., & Ryan, R. M. (1999b). The undermining effect is a reality after all—Extrinsic rewards, task interest, and self-determination: Reply to Eisenberger, Pierce, and Cameron (1999) and Lepper, Henderlong, and Gingras (1999). *Psychological Bulletin*, 125(6), 692-700. doi:10.1037/0033-2909.125.6.692
- Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2007, 05). Outcome for Children with Autism who Began Intensive Behavioral Treatment Between Ages 4 and 7. *Behavior Modification*, 31(3), 264-278. doi:10.1177/0145445506291396
- Gresham, F. M., & MacMillan, D. L. (1998). Early intervention project: Can its claims be substantiated and its effects replicated?. *Journal of autism and developmental disorders*, 28(1), 5-13.
- Grolnick, W. S., & Ryan, R. M. (1990, 03). Self-Perceptions, Motivation, and Adjustment in Children with Learning Disabilities. *Journal of Learning Disabilities*, 23(3), 177-184. doi:10.1177/002221949002300308
- Grusec, J. E., & Kuczynski, L. (1997). *Parenting and children's internalization of values: A handbook of contemporary theory*. J. Wiley.
- Guardia, J. G., & Ryan, R. M. (2007, 12). Why Identities Fluctuate: Variability in Traits as a Function of Situational Variations in Autonomy Support. *Journal of Personality*, 75(6), 1205-1228. doi:10.1111/j.1467-6494.2007.00473.x
- Guardia, J. G., Ryan, R. M., Couchman, C. E., & Deci, E. L. (2000). Within-person variation in security of attachment: A self-determination theory perspective on attachment, need fulfillment, and well-being. *Journal of Personality and Social Psychology*, 79(3), 367-384. doi:10.1037/0022-3514.79.3.367
- Howlin, P., Magiati, I., & Charman, T. (2009). Systematic Review of Early Intensive Behavioral Interventions for Children With Autism. *American Journal on Intellectual and Developmental Disabilities*, 114(1), 23. doi:10.1352/2009.114:23;nd41
- Koegel, R. (2011). O. Ivar Lovaas (1927-2010). *American Psychologist*, 66(3), 227-228. doi:10.1037/a0022693
- Koestner, R., Ryan, R. M., Bernieri, F., & Holt, K. (1984, 09). Setting limits on children's behavior: The differential effects of controlling vs. informational styles on intrinsic motivation and creativity. *Journal of Personality*, 52(3), 233-248. doi:10.1111/j.1467-6494.1984.tb00879.x

- Kohn, A. (2010). *Punished by rewards: The trouble with gold stars, incentive plans, A's, praise, and other bribes*. Houghton Mifflin.
- Kupferstein, Henny. 2018. "Evidence of Increased PTSD Symptoms in Autistics Exposed to Applied Behavior Analysis." *Advances in Autism* 4(1): 19–29.
- Lovaas Center (2017). Dr. Ole Ivar Lovaas | Pioneer of Applied Behavior Analysis (ABA). Retrieved from <http://thelovaascenter.com/about-us/dr-ivar-lovaas/>
- Lovaas, O. I., Berberich, J. P., Perloff, B. F., & Schaeffer, B. (1966a, 02). Acquisition of Imitative Speech by Schizophrenic Children. *Science*, 151(3711), 705-707. doi:10.1126/science.151.3711.705
- Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55(1), 3-9. doi:10.1037//0022-006x.55.1.3
- Lovaas, O. I. (1964). Control of food intake in children by reinforcement of relevant verbal behavior. *The Journal of Abnormal and Social Psychology*, 68(6), 672-678. doi:10.1037/h0047612
- Lovaas, O. I., Schaeffer, B., & Simmons, J. Q. (1965). Building social behavior in autistic children by use of electric shock. *Journal of Experimental Research in Personality*.
- Lovaas, O. I., Schreibman, L., Koegel, R., & Rehm, R. (1971a). Selective responding by autistic children to multiple sensory input. *Journal of Abnormal Psychology*, 77(3), 211-222. doi:10.1037/h0031015
- Lovaas, O. I., Koegel, R., Simmons, J. Q., & Long, J. S. (1973). Some generalization and follow-up measures on autistic children in behavior therapy1. *Journal of Applied Behavior Analysis*, 6(1), 131-165. doi:10.1901/jaba.1973.6-131
- Lovaas, O. I., Schreibman, L., & Koegel, R. L. (1974, 06). A behavior modification approach to the treatment of autistic children. *Journal of Autism and Childhood Schizophrenia*, 4(2), 111-129. doi:10.1007/bf02105365
- Lovaas, O. I., & Smith, T. (1989, 03). A comprehensive behavioral theory of autistic children: Paradigm for research and treatment. *Journal of Behavior Therapy and Experimental Psychiatry*, 20(1), 17-29. doi:10.1016/0005-7916(89)90004-9
- Lovaas, O., Freitag, G., Kinder, M. I., Rubenstein, B. D., Schaeffer, B., & Simmons, J. Q. (1966b, 10). Establishment of social reinforcers in two schizophrenic children on the basis of food. *Journal of Experimental Child Psychology*, 4(2), 109-125. doi:10.1016/0022-0965(66)90011-7
- Lovaas, O., Freitag, G., Gold, V. J., & Kassorla, I. C. (1965, 03). Experimental studies in childhood schizophrenia: Analysis of self-destructive behavior. *Journal of Experimental Child Psychology*, 2(1), 67-84. doi:10.1016/0022-0965(65)90016-0

- Lovaas, O., Litrownik, A., & Mann, R. (1971b, 02). Response latencies to auditory stimuli in autistic children engaged in self-stimulatory behavior. *Behaviour Research and Therapy*, 9(1), 39-49. doi:10.1016/0005-7967(71)90035-0
- Lovaas, O., & Schreibman, L. (1971c, 11). Stimulus overselectivity of autistic children in a two stimulus situation. *Behaviour Research and Therapy*, 9(4), 305-310. doi:10.1016/0005-7967(71)90042-8
- Lovaas, O., Freitas, L., Nelson, K., & Whalen, C. (1967, 08). The establishment of imitation and its use for the development of complex behavior in schizophrenic children. *Behaviour Research and Therapy*, 5(3), 171-181. doi:10.1016/0005-7967(67)90032-0
- Lovaas, O. I. (1981). *Teaching developmentally disabled children: The me book*. Pro-ed.
- Özerk, K., Veal, G. D., Eikeseth, S., & Özerk, M. (2016). Ole Ivar Lovaas--His Life, Merits and Legacy. *International Electronic Journal of Elementary Education*, 9(2), 243-262.
- Reichow, B., & Wolery, M. (2008, 06). Comprehensive Synthesis of Early Intensive Behavioral Interventions for Young Children with Autism Based on the UCLA Young Autism Project Model. *Journal of Autism and Developmental Disorders*, 39(1), 23-41. doi:10.1007/s10803-008-0596-0
- Rekers, G. A., & Lovaas, O. I. (1974). Behavioral treatment of deviant sex-role behaviors in a male child. *Journal of Applied Behavior Analysis*, 7(2), 173-190. doi:10.1901/jaba.1974.7-173
- Reynolds, B. S., Newsom, C. D., & Lovaas, O. I. (1974, 12). Auditory overselectivity in autistic children. *Journal of Abnormal Child Psychology*, 2(4), 253-263. doi:10.1007/bf00919253
- Ryan, R. M., (2013), "Opening Remarks from the 5th Conference on Self-Determination Theory." *Self-Determination Theory*. selfdeterminationtheory.org/youtubehighlights-opening-remarks-5th-conference-self-determination-theory/.
- Ryan, R. M., & Deci, E. L. (1996, 01). When Paradigms Clash: Comments on Cameron and Pierce's Claim That Rewards Do Not Undermine Intrinsic Motivation. *Review of Educational Research*, 66(1), 33-38. doi:10.3102/00346543066001033
- Ryan, R. M., & Deci, E. L. (2001). On happiness and human potentials: A review of research on hedonic and eudaimonic well-being. *Annual review of psychology*, 52(1), 141-166.
- Ryan, R. M. (1982). Control and information in the intrapersonal sphere: An extension of cognitive evaluation theory. *Journal of Personality and Social Psychology*, 43(3), 450-461. doi:10.1037/0022-3514.43.3.450
- Ryan, R. M., Kuhl, J., & Deci, E. L. (1997, 12). Nature and autonomy: An organizational view of social and neurobiological aspects of self-regulation in behavior and development. *Development and Psychopathology*, 9(04). doi:10.1017/s0954579497001405

- Ryan, R. M., & Connell, J. P. (1989). Perceived locus of causality and internalization: Examining reasons for acting in two domains. *Journal of Personality and Social Psychology*, 57(5), 749-761. doi:10.1037/0022-3514.57.5.749
- Ryan, R. M., Mims, V., & Koestner, R. (1983). Relation of reward contingency and interpersonal context to intrinsic motivation: A review and test using cognitive evaluation theory. *Journal of Personality and Social Psychology*, 45(4), 736-750. doi:10.1037/0022-3514.45.4.736
- Ryan, R. M., & Deci, E. L. (2017, 1985). *Self-determination theory: Basic psychological needs in motivation, development, and wellness*. Guilford Press.
- self-determination. 2017. In Merriam-Webster.com.
Retrieved Nov 30, 2017, from <https://www.merriam-webster.com/dictionary/>
- Sequenzia, A. (2015, February 11). My Thoughts on ABA. Retrieved February 12, 2018, from <https://autismwomensnetwork.org/my-thoughts-on-aba/>
- Shae, N. M. (2013). Perceived Autonomy Support in Children with Autism Spectrum Disorder. *Autism-Open Access*, 03(04). doi:10.4172/2165-7890.1000114
- Schopler, E., Short, A., & Mesibov, G. (1989). Relation of behavioral treatment to "normal functioning": Comment on Lovaas. *Journal of Consulting and Clinical Psychology*, 57(1), 162-164. doi:10.1037//0022-006x.57.1.162
- Schreibman, L., & Lovaas, O. I. (1973). Overselective response to social stimuli by autistic children. *Journal of Abnormal Child Psychology*, 1(2), 152-168. doi:10.1007/bf00916110
- Sheldon, K. M., Ryan, R. M., Rawsthorne, L. J., & Ilardi, B. (1997). Trait self and true self: Cross-role variation in the Big-Five personality traits and its relations with psychological authenticity and subjective well-being. *Journal of Personality and Social Psychology*, 73(6), 1380-1393. doi:10.1037//0022-3514.73.6.1380
- Smith, T., & Lovaas, I. O. (1998, 01). Intensive and Early Behavioral Intervention with Autism. *Infants & Young Children*, 10(3), 67-78. doi:10.1097/00001163-199810030-00010
- Stewart, M., McGillivray, J. A., Forbes, D., & Austin, D. W. (2016, 02). Parenting a child with an autism spectrum disorder: A review of parent mental health and its relationship to a trauma-based conceptualisation. *Advances in Mental Health*, 15(1), 4-14. doi:10.1080/18387357.2015.1133075
- The Rehabilitation Act of 1973, (Pub.L. 93 112, 87 Stat. 355, enacted September 26, 1973), is a federal law, codified as 29 U.S.C. § 701 et seq.
- Wright, J. (2015, December 10). Autism's Lost Generation. Retrieved December 02, 2017, from <http://www.theatlantic.com/health/archive/2015/12/the-lost-adults-with-autism/419511/>