

COMMENT

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Dear Verabeth,

It has been a long while since I have written to you, and even a longer time since you sent me the essay "I'm Nobody". It is a very moving piece of writing, and I have to admit that it is very flattering to me. More so since it seems hard to believe that this therapy took place more than 40 years ago.

Let me congratulate you on all your accomplishments in this vast interim. It is no small measure that you are now enrolled in the University of Iowa Creative Writer's Workshop. And that this essay was the non-fiction example that helped that faculty recognize your creative potential. You are an extremely creative person. And I feel a somewhat vicarious but still genuine sense of pride in this particular achievement, not to mention the fact that after therapy you went on to a most productive nursing career, earning even a graduate degree and contributing very significantly to the mental retardation movement in general and the understanding of Fragile X Syndrome in particular.

It is about this understanding that I am writing at this time. It seems to me that this essay has the potential to significantly expand that understanding. Your essay is about the meaning of psychotherapy in a most subjective perspective, and as such beautifully describes how one person can benefit so momentously in resolving the anchoring conflicts which might hold any person back from tapping deeper and more positive motivations. Your description of the necessary empathy is moving. And your building of trust and obliteration of the bathyspheric walls of mistrust are not only appropriate descriptions, but well-stated in terms of the process of ordinary psychotherapy. However, what is most unique about your descriptions is what they might add to the perspectives of behavioral genetics.

But first should be a consideration of the meaning of "mental retardation." These descriptions remain very difficult for you (as they might for any parent to assimilate) after they are applied to a particular child. For you, it might seem that David had all of these attributes and developmental "deficiencies," such as beginning to talk so late -- or his motor skills being not only inept and long-awaited, but then awkward and ill-coordinated. When these were once achieved, he was in "perpetual motion:" off and away! And what was more awful, not wanting to be touched. (Was that in part not wanting to be stifled or suppressed? -- once he had achieved some modicum of control or independence?) He was still learning to "round" his "D"s at age 11. And almost impossible to direct or parent because you were unable to communicate with him according to ordinary age-appropriate expectations which might apply to normally developing children. Many of these traits are shared with most children called "mentally retarded," but then some were some now recognized behavioral genetic traits of his Fragile X Syndrome.

Of course at the time of your therapy, general knowledge and medical science had not yet advanced to an understanding of the composition of sex chromosomes or to a possible diagnosis of what later became the "Fragile X Syndrome." Consequently, you were in the position of struggling through the list of "descriptors" presented in your essay. And as a result, you were emotionally plummeting at that time through the span of an extensive search for a "reason why." You state that experience well in reasoning that if you could only find the cause, then there might be the chance to "fix it, fix it, fix it." However, even when science eventually provided you with the reason why, all you discovered was that you were not able to achieve that highly desired and dreamt of hypothetical cure. You were in reality left with only the sole alternative of accepting a course of providing the best possible care for you clearly "different" sons. Understanding the reason why was not the panacea you had hoped for. It was simply the soul-wrenching acceptance of a unique and deviant life-course for your loved ones.

Back to the points within your essay which are excellent descriptors of what has been recognized as the behavioral genetics of the Fragile X Syndrome. You state it well in the fact that these boys lacked the charm of what you consider "well behaved" Down Syndrome children. The Fragile X child characteristically avoids personal touch or human contact. Their evasive eye gaze was one of the first noted behavioral characteristics of this syndrome. This personal remoteness or detachment (not wanting to be held or touched) made it all the more difficult to establish the necessary rapport to facilitate normal parenting. Their hyperactivity or "perpetual motion" was also early noted to be a most taxing or wearing parental demand. And their unexplained "misbehaviors" were not what they learned from unaffected siblings or a result of parental example. Their parents were often providing and capable of teaching acceptable behavioral reactions within the home setting, as they did with their other children. Such facts of behavioral genetics have been fairly well recognized at the current point of time.

However, the most significant contribution your essay might make upon broader publication, is in the understanding of the carrier state. In desiring to publish this, you must realize that you are making a very personal and extreme disclosure on your

part. It does seem that in originally writing this essay, you realized this fact and were courageous enough to undertake such an attempt. Your own "flight of ideas," jumping from one concept to another, and racing thought processes, are clearly symptomatic of the carrier state. Such trait descriptions should serve to advance the understanding of what are termed the "learning disabilities" of the school-aged carrier girls. The concern or worry that this might be a symptom of schizophrenia also is a natural consequence of experiencing this disturbance of normal thought processes. Your recognition that there were no "auditory or visual hallucinations" should also expand the process of differential diagnosis. And the inability to establish an effective agentic operator, a self or "I", provides clear understanding why so many carriers or affected males continue to operate in the third person as a "her" or "him".

This latter trait, of course, is shared by other forms of mental disturbance, and is seen frequently as being reversed in the process of therapy. The movement toward an agentic or operator "I" has been long recognized as one of the indicators of successful process in therapy. It is part of the redefinition of self or the finding of a correct or most fitting name during the therapeutic process. This is your "baptism of receiving a name" or becoming an "I." This you have tied with the necessity of empathy, and I can only underscore your moving and illustrative example of empathy being the "pair or us" sitting there sharing this same space and time (and thoughts).

Of course your strong religious perspective colors this essay. It even tones your conceptualization of me as therapist to be a father confessor or and through memory distortion making my degree come from Chicago's Loyola University and not from my actual alma mater, The University of Chicago. That seemed appropriate in what I saw, and what you grasped as, your deepest need in therapy: that of finding "spiritual peace." And that you most aptly described as the main achievement of your therapeutic experience.

Such then, is my perspective of what you have written and what may be its potential for promoting understanding of what we now recognize (but did not then) as the behavioral effects of a definite genetic syndrome involving the lives of probably the majority of what might be termed "genetically determined mental retardation". Your desire to publish these thoughts is indeed courageous. However, I find that I need once again professionally to warn you that there are risks in disclosing so much of your person, in the effect that it could expose you to possible ridicule or embarrassment in the future. But I gather you are willing to assume such risk in weighing the benefits of easing the pain of others who might discover they are in the situation you once found yourself. Through this means you can facilitate the more expedient alleviation of such pain and promote the inner peace and resolution that you so diligently sought.

I can only commend you for such courage, and for such determination to seek these desired resolutions.

Most sincerely,
Bruce Cushna, Ph.D.