

The Experience of Infantile Autism: A First-Person Account by Tony W.¹

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A first-person account of the experience of autism is presented by a 22-year-old man who was first evaluated at the Yale Child Study Center at 26 months of age. His history and current status are reviewed. Factors related to outcome and diagnostic issues are discussed. Such accounts may be helpful in guiding research.

First-person accounts of the experience of psychiatric illness have appeared with greater frequency in recent years (Sommer & Osmond, 1983; Bliss, 1980). Not surprisingly, autistic individuals have been less able to produce such accounts since the characteristic linguistic and cognitive deficits of such persons generally preclude clinicians and investigators from having direct verbal access to their experience. Parental accounts of autistic children have appeared (e.g., Park, 1983), and the adult recollections of one 31-year-old man, original diagnosed by Kanner, have been published (Bemporad, 1979).

In this report we present a young adult's account of his own experience of infantile autism. Before the presentation of his statement, his history and current functioning are reviewed; we then discuss issues of diagnosis and prognosis.

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Tony W. (a pseudonym) recently returned to the Yale Child Study Center at 22 years of age in order to gain access to the records of his initial evaluation done 20 years previously. In the course of his many meetings with us he decided to write his own account of the experience of autism.

At the time of his initial referral to the Child Study Center at 26 months of age, Tony, the youngest of three children, was a nonverbal, poorly related child whose parents' presenting complaints were his lack of speech and poor social relatedness. On developmental examination all aspects of his development were delayed. Gross and fine motor performances were more typical of an 18-month-old, personal-social and language performances were below the 1-year level; only in the adaptive area of the examination did he achieve some successes at or near his age level. His parents reported that from the first weeks of life Tony avoided human contact, was difficult to hold, never smiled responsively, and was unusually preoccupied with his hands and spinning objects. He also had a history of feeding difficulties. At the time of initial evaluation his absent language, lack of attachment to his parents or other people, bizarre responses to the environment, and aberrant motor patterns (toe walking and stereotyped hand movements) supported the diagnosis of infantile autism.

Tony was subsequently enrolled in a therapeutic nursery school program at the Child Study Center; he remained in this program for several years before and during his entry into a special education program in the public school system. During that time he was seen for intensive education and psychotherapy and made significant gains developmentally and socially. By 3 years of age he began to communicate meaningfully, although his speech was remarkable for echolalia. He was seen yearly for developmental evaluation. By 5 years 11 months of age his Stanford-Binet IQ score was 92. As he indicates in his statement, he was subsequently transferred to a private school setting, where he remained until his entrance to high school, which he left after the 10th grade.

As an adolescent, Tony had sporadic psychiatric contact and was very aware of his feelings of being "different" from other people. He joined the armed forces only to be quickly discharged.

At the present time he works as an assembler in a local industry. He lives by himself and has managed to make a few superficial friendships, although his attempts to secure a girl friend have been uniformly unsuccessful. His current WAIS scores (94 Verbal, 92 Performance, 93 Full Scale) are a testament to his intellectual abilities. The patterns of his scores on the WAIS subtests indicate peak performance on object assembly and poorest performance on vocabulary and digit symbol tasks; as for many autistic persons, his performance on IQ tests has been stable and has predicted his ultimate outcome (Lockyer & Rutter, 1970). Apart from his painful

awareness of being socially isolated and unable to be empathetic, he reports difficulties with various symptoms of anxiety, periodic alcohol abuse, and unusual sensory experiences. He has occasionally used substances other than alcohol in an attempt to diminish his pervasive anxiety and to feel more socially adequate. Interestingly, his one experience with amphetamine, which elevates brain dopaminergic activity (Young, Kavanagh, Anderson, Shaywitz, & Cohen, 1982), was extremely unpleasant since his stereotyped behaviors reappeared for the first time in years. Physical and neurological examination are currently within normal limits.

In the following narrative, Tony presents his own impressions of “growing up autistic.” For purposes of clarity we have added punctuation and clarification of spelling for meaning; such additions are enclosed in parentheses. Tony W.’s statement stands by itself as a valiant attempt to communicate his experience to others in the face of disability.

AUTISM: “THE DISEASE OF ABOMINATION”

Tony W.

I was living in a world of daydreaming and Fear revolving about my self I had no care about Human feelings or other people. I was afraid of everything! I was terrified to go in the water swimming, (and of) loud noises; in the dark I had severe, repetitive Nightmares and occasionally hearing electronic noises with nightmares. I would wake up so terrified and disoriented I wasn't able to Find my way out of the room for a few minutes. It felt like I was being dragged to Hell. I was afraid of simple things such as going into the shower, getting my nails clipped, soap in my eyes, rides in the carnival—except the Spook house I love it , I also like Hellish environments such as spookhouses at the Carnival, Halloween, and movies—horror. I daydreamed a lot and tried to actively communicate and get into that world. I remember Yale Child Study Ctr. I ignored the doctors and did my own thing such as make something and played or idolize it not caring that anybody was in the room. I was also very hat(e)full and sneaky. I struggled and breathed hard because I wanted to kill the guinea pig; as soon as the examiner turned her back I killed it. I hated my mother because she try to stop me from being in my world and doing what I liked; so I stopped and as soon as she turn her back I went at it again. I was very Rebellious and sneaky and destructive. I would plot to kill my mother and destroy the world. Evil thing astonished me such as an H.Bomb. I loved cartoons and their environments. I also (had) a very warped sense of humor and learned perverted thing(s) very

quickly. I used to lash out of control and repeat sick, perverted Phrases as well as telling people violent, wild, untrue things to impress them.

In school I learned somethings very quickly but other were beyond learning comprehension. I used to disrupt the whole class and love to drive the teachers nuts. When I first started talking—5 years old—I started talking about an incident that happened a year before. I was obsessed with certain things and played in my own way. I make things with Garbage or Junk and Play with them. I like mechanical Battery Power toys or electronic toys. Regular toys such as toy trucks, cars that weren't battery powered didn't turn me on at all. I was terrified to learn to ride the bicycle. One thing I loved that not even the Fear could stop was Airplanes. I saw an air show the planes—f4s—were loud. I was always(s) Impressed by Airplanes. I drew pictures and had several Airplane models. The Test came when we went to D.C. I was so Anxious and Hyper to go on the plane I drove my Parents nut. The only peace they had is when I heard the turbines revving at the end of the runway. Then I knew we were taking off. Soon as the plane took off I was amazed. I started to yell y(a)h HO! I loved every minute of it. I always loved Hi tech thing(s)—Planes, Rockets. I watched a lot of coverage of the rocket launchings, moon landings, and splash downs; I love it. I like Plants too. I grew a lot of Plants too. And I liked Animals too, after the gunia pig killing. I hated sports and still do. (I was) horrified (the) first time I saw my own blood—cut I also was very hard to assure or convince and always need reassurance and still do today. I don't or didn't trust anybody but my self—that still (is) a problem today. And (I) was and still (am) very insecure! I was very cold Hearted too. It(t) was impossible for me to Give or Receive love from anybody. I often Repulse it by turning people off. That is still a problem today and relating to other people. I liked things over people and didn't care about People at all. I was Very Fussy about everything and demanded comfort and pleasure and (was) Very Hyperactive and smelled thi(n)gs all the time. I spent hours Flicking books and was thirst(y) all the time and drank a lot—not booze. And was very Fussy about eating, loved sweets and Junk Food. I was very unthankful and Greedy and hard to satisfy. And had and still have some mental blocks and great difficulty paying attention and listening to people and was very eas(i)ly distracted. I demanded to be amused by people and got bored very eas(i)ly and can't deal with stress. And had great difficulty fulfilling obligations. I would hear electronic Noises and have quick seizures (seizures) in bed and many other ph(y)sical problems. Often I have to be Force to get things done and (was) very uncoordinated. And was very Nervious about everything. And Feared People and Social Activity Greatly. Then I was sent to (another school). My behavior hasn't change(d) at all or Problems listed before But more physical problems started shortly before and after leaving (this

school). I hated and rebelled. (This other school) was mostly cold harked discipline. There was very little physical abuse by the staff. Finally My Shrink Prescribed (prescribed) Trifluoperazine (Trifluoperazine) to calm my behavior. The only physical, medical attention I had was a quick 5 minute physical and shots and a blood test to make sure I wouldn't choke by eating 4 Trifluoperazines a day. Those pills knock me out. I had to Fight to stay awake. I complained to the shrink and all he said was my body had to get used to it. He was only 25% right. Once I got used to it I barely managed to stay awake. But I was more of a vegetable than I was before. I was drowsy all the Time. Shortly before leaving (this school) physical problems were on the Climb—pounding head migraines, headaches, chronic peeing, seeing white bubbles, heart pains, and Chronic Fear of Dying. After getting out I complained to my shrink about (it) and my dad—I lived w/my father after (this school)—my parents divorced. I was deprived (of) physical treatment because of my mental illness. My mother all(ways) wanted Medical testing done to see If There was a Medical problem causing This hellish disease. It was never done and I was often told she was crazy hypochondriac (hypochondriac) and the physical problem was also caused by nerves and it was all in my head. I believed it all for a long Time! And (I) was prescribed Valium for a short while.

After I left (this school) The physical problems continued and The list gets longer. I lived with my father and the(n) saw the so called normal, sick teenage world. I was 14. I set my will (to) be normal like everybody else. (I) looked up to people in school and did what they did to be accepted and put (up) more of a show to hide the problems and be Normal. I forced(d) my self to Know all the top rock groups, smoke pot, and drink and (tried to) have a girl friend. This was the 9th grade and 10th. I constantly got in trouble in school and did some(e) real crazy things to be cool. Like everybody else I thought I was all normal. Most of it was a failure. More people hated me than ever. My interests were destroyed because I thought they weren't normal. Things were going bad at home. My Father and I were not getting along because of trouble in school. I wasn't getting along with No one. I got my (drivers) license and tried to impress people at school and girls by driving like a nut. IN tenth grade I quit school and worked washing cars and work(ed) many other Jobs too. I was very depressed and Hyper at work. I got along with my boss at all my Jobs. I tend to get lazy and had trouble getting along with other people. So in (an) effort to keep my Jobs I avoided many people. I found It a lot easier to get along with older people and FEARED People my age because of school. I went into to the army and got in lots of Fights with people. So I got discharged (discharged). I also have great Trouble getting thing(s) organized and misunderstand almost everything. I worked a few more Jobs and hung around w/some Crazy people I knew from school and got drunk a lot and did destructive things,

Magnified Fears and Peronia on pot. I never got Fired from a job. My problems haven't changed at ALL from early childhood. I was Just able to Function. And it still (is) the same today—1983. Plus more physcial problems in 1982 knowing that NONE of these problems are gone but only sepreessed (suppressed) by Physcatric (Psychiatric) treatment. Then (I) insisted on their was a medical problem but IT programed that Medical Help was a cop out and after (I) Find out more truth about lie and rebelling and hating its and doubting it. And then all the childhood problems and physcial problems starting eating me like a cancer. I then felt The medical help in one of the only hopes for my well being and (that of) Approx. 500,000+ Autistic kids.

DISCUSSION

Much of the current understanding of the autistic syndrome has resulted from information collected in numerous follow-up studies (see DeMyer, Hingtgen, & Jackson, 1981, for a review). As information from such studies has become available, we have achieved a better understanding of the course, prognosis, and phenomenology of the disorder. The poignant and vivid account provided by Tony W. and his case presents several interesting questions. Before discussing the issues of prognosis and diagnosis in this particular case, features of Tony's history and of his account that are both typical and atypical merit review.

The pattern of his performance, both on early developmental examination and more recently on the WAIS, are typical of many autistic individuals (Rutter, 1970). Tony continues to exhibit the pattern of good perceptual-motor, problem-solving, and rote memory skills accompanied by linguistic and social deficits that characerized his early performance. His detailed account reflects those cognitive strengths along with persisting difficulties. His descriptions of numerous fears, awareness of his lack of empathic relatedness, unusual sensitivity to sensory stimuli, and other symptoms are, in our experience, typical of higher-functioning autistic adults (Bemporad, 1979). The degree of anger, fantasy, and aggressive impulses he relates are, however, less typical. More commonly, such individuals are relatively more placid, conventional, and apparently less dysphoric. However, they may have aggressive thoughts expressed with a calm voice, e.g., "I'll murder him" said about a bus driver with whom the patient is angry.

In general, the outcome for autistic children is quite poor (Rutter, 1970; DeMyer et al., 1973). By any of a number of outcome criteria Tony appears to have experienced a remarkably good outcome; he can engage in gainful employment, can be relatively self-supportive, and is able to sustain an independent existence. He continues to experience a variety of dif-

difficulties related to his lack of social relationships and anxiety of which he is aware. In retrospect, the favorable prognostic factors in Tony's case included his rapid developmental gains during his first years of treatment (especially in expressive language skills), the absence of signs of CNS dysfunction, and his intellectual level. Such factors have previously been reported to be indicators of good prognosis (Rutter, 1970; Lockyer & Rutter, 1970; DeMyer et al., 1973). As is true for most autistic children with good outcomes, Tony was able to acquire communicative speech by age 5 and his intellectual skills have been relatively stable since that time (DeMyer et al., 1973, 1981). The improved relatedness following the development of speech may also have been a favorable sign; in two cases of apparent "recovery" from Kanner's syndrome this appears to have been the case (Gajzago & Prior, 1974). Tony's growing awareness of being different and his strong desire to develop interpersonal relationships during adolescence may also have been a good prognostic indicator. In Kanner's (1973) follow-up of 96 autistic children, such an awareness appeared to have motivated change in some individuals. However, the question of why Tony's outcome was comparatively good while that of most other autistic children is poor remains a matter of speculation.

Tony's case also raises several diagnostic issues. In our opinion he no longer meets DSM III criteria (APA, 1980) for Infantile Autism but the application of DSM III criteria to such higher-functioning individuals is generally problematic. While Tony clearly had an early-onset disorder characterized by bizarre responses to the environment, a pervasive lack of responses to others, and linguistic abnormalities characteristic of autism, he quite obviously is no longer *pervasively* unresponsive to other people. Accordingly, while Tony no longer meets DSM III criteria for infantile autism, his past history and the persistence of his social and communicative disabilities are consistent with what DSM III terms "infantile autism, residual state." The unusual sensory experiences ("electronic noises") and communication patterns that Tony exhibits also deserve comment since they might, initially, be mistaken for the thought disorder and hallucinatory experiences of schizophrenia. In our contact with higher-functioning autistic or "residually" autistic individuals such experiences are not uncommon. Unlike the delusions and hallucinations of the schizophrenic, however, such experiences are not well elaborated or systematized. The DSM III criteria for autism that exclude delusional thinking and hallucinatory experiences thus must be considered in a broad developmental context in making the diagnosis in higher-functioning individuals.

Another diagnostic possibility for the higher-functioning autistic individual such as Tony is Asperger's Syndrome of Autistic Psychopathy (Wing, 1981); this syndrome, which may be a variant of infantile autism, is

apparently characterized by abnormal patterns of communications, odd social interaction, motor incoordination, and excellent rote memory skills. As a group, such individuals appear to exhibit remarkably good intelligence. In Tony's case the relative preservation of motor development, the lack of unusual islets of ability, and the abnormal sensory responses suggest that such a diagnosis is less appropriate. However, the lack of research and clinical experience with such persons makes such a differentiation difficult.

The remarkable progress Tony has made in coping with the very profound stress imposed by his disabilities and his awareness of them highlights the potential importance of engaging individuals like Tony in research efforts in an attempt to increase our understanding of basic mechanisms of coping and adaptation. Tony and similar individuals also can contribute to our understanding of the core problems and experience of infantile autism (Cohen, 1980).

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