

Developmental and Psychiatric Disorders in Children with Blindness or Visual Impairment

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The recent appointment of David Paterson as Governor of New York, the first legally blind chief state executive, has generated curiosity and renewed conversation about conditions of visual impairment and legal blindness and how these conditions shape individual creativity and resourcefulness (Kuusisto, 3/14/08).ⁱ The governor lost his vision because of a childhood illness and accordingly, in his youth, would have been numbered among children with blindness or visual impairment (B/VI). While B/VI is said to be not very common among children, just how commonly it appears at particular times, is an ongoing concern of the Developmental Disabilities Surveillance Program conducted in a five county area around Atlanta, Georgia by the Center for Disease Control (CDC).ⁱⁱ In 2000, the prevalence of visual impairment at age 8 years old was 1.2/1000. The American Foundation for the Blind (AFB) and the National Federation of the Blind (NFB)^{iii iv} agree upon 93,600 as the approximate number of our students nationwide with B/VI (10,800 of them also have deafness). According to the AFB, 55,200 of our students meet criteria for legal blindness. In their chapter devoted to psychiatric conditions in youth with perceptual impairment, Gonzales and Chess extensively cite a 1977 study conducted by Jan et al. in Vancouver, BC, which reported 43% of youth with B/VI were free of psychiatric diagnoses^v. This finding apparently still has currency, albeit estimates of mental health by professionals now serving the needs of youth at Indiana School for the Blind and Visually Impaired (ISBVI) are somewhat more generous simply because the number of students who rely upon extramural mental health services is not known (Johnston, personal communication, 2008)^{vi}. Findings in 1977 among the children in Vancouver with B/VI in domains of personal and social emotional development included difficulties with clinging and separation problems; more frequent major fears with predominating themes differing from those of same aged sighted children (namely: fears of harm befalling an attachment figure and physical danger versus fears of psychological harm, respectively); and more restrictive patterns of play. ISBVI social work staff are impressed by the steadily growing number of enrollees in whom B/VI is accompanied not only by developmental disorder but also adverse life experiences. At ISBVI, psychiatric concerns range widely in severity and include the entire array of adjustment, anxiety (including Post Traumatic Stress Disorder) and mood disorders, cases of disrupted attachment, attention deficit hyperactivity and behavior disorders and, of course developmental disorders. Since ISBVI serves the entire state, dormitory living is made available through the week for those students obliged to travel long distances from home. However, while accommodating the special needs that occur in conditions of B/VI including social skill building group work and providing many enrichment experiences besides, ISBVI does not provide what mental health professionals commonly understand by the terms, 'individualized psychotherapy' 'group psychotherapies' or 'family therapy' let alone 'therapeutic residential programs' (Wilkinson and Webster, personal communications, 2008).^{vii} Accordingly those students residing in the dormitories who require more intensive mental health services, such as outpatient therapy, may be burdened to find it on weekends. It is worse still for those youth who are seriously and persistently unsafe with either themselves or others and who do not respond to a behavioral care plan based on sound functional behavioral analysis. For them, the question

becomes: 'Are these youth better served in a residential program (assuming one can be found willing to take the referral) which must then rely on the local educational administration (LEA) to ensure their B/VI special educational needs will be met?' Alternatively, should the school be enabled by the legislature to enlarge both its capacity and its competency along the continuum of therapeutic interventions?

The CDC estimates that one half to two thirds of the children with B/VI in the aforementioned surveillance program also had one or more developmental disabilities. Among co-morbid developmental disabilities are found cerebral palsy, intellectual disabilities and autism spectrum disorder (ASD).^{viii}

The diagnosis of an ASD in youth with B/VI is hampered by difficulties adapting and meaningfully calibrating visually loaded assessment scales (e.g. the ADOS which nonetheless is sometimes used) for autism (Johnston, personal communication, 2008).^{ix} Drawing from their experiences, contributors in the field (e.g. Pawtelko, 2002 and Gense and Gense, 2002)^{x xi} provide useful comparisons of characteristics of youth who are sighted without ASD, those with B/VI and those with B/VI plus ASD. In addition a more scholarly consideration of the conditions of concern may be guided by contributions to be found in *Autism and Blindness, Research and Reflections*, edited by Linda Pring.^{xii} Among neurodevelopmental conditions with B/VI, one called Septo-Optic Dysplasia (SOD) has seemed to this clinician particularly likely to bring up questions of ASD. SOD is a heterogeneous group of disorders that variably include optic nerve hypoplasia and dysgenesis of the septum pellucidum. Clinically, SOD most commonly involves VI and pituitary hypofunction but there may also be malformation of cortical organization (sometimes referred to as SOD-schizencephaly or SOD-PLUS. The latter condition may be more often associated with ASD.^{xiii}

The prevalence of B/VI may be considered uncommon in children, but among our children who have B/VI there is greater than ordinary risk for developmental disabilities and childhood psychiatric disorders. The needs are great, but, sad to say, inadequately met: for teachers with specialized in educational skills that address not only B/VI but also ASD, for mental health professionals who are readily available to respond to ASD and other psychiatric conditions that are even less likely to spare youth with B/VI than those who are sighted, for collaboration between state and university to develop better assessments and treatment techniques.

ⁱ Kuusisto S (3/14/08): The vision thing. **New York Times**. Accessed at <http://www.nytimes.com/2008/03/14/opinion>.

ⁱⁱ CDC. Accessed 3/5/08 at <http://www.cdc.gov/ncbddd/dd/vision3.htm>

ⁱⁱⁱ AFB. Accessed 3/5/08 at <http://www.afb.org>. See Quick Facts

^{iv} NFB. Accessed 3/5/08 at <http://www.nfb.org>. See Blindness Statistics

^v Gonzales M and Chess S (2002): Psychiatric evaluation of perceptually impaired children: hearing and visual impairments. In **Child and Adolescent Psychiatry, A Comprehensive Textbook**, Third Edition ed. M. Lewis. Lippincott Williams and Wilkins, Philadelphia, pp. 630-45.

^{vi} D Johnston, PhD, Psychologist ISBVI.

^{vii} M Wilkinson and J Webster, *Social Workers*, ISBVI.

^{viii} Op cit. CDC.

^{ix} Op cit. D. Johnston, PhD.

^x Pawletko T (2002): Autism and visual impairment. *FOCAL Points*, Fall 2002, volume 1 issue 2; Accessed 4/8/08 via Nebraska Center for the Education of Children Who are Blind or Visually Impaired at <http://www.ncecbvi.org/autism.htm> also at the same address, see Pawletko and Rocissano (7/18/2000): Autism in the visually impaired child, Psychology Department Maryland School for the Blind, AER/Denver.

^{xi} Gense M and Gense J (2002): Autism spectrum disorder in learners with blindness /vision impairments comparison of characteristics. Accessed 4/8/08 at

<http://www.focusfamilies.org/focus/docs/blindnessandautism.pdf>

^{xii} **Autism and Blindness Research and Reflections**. Ed. L. Pring, Whurr Publishers, London, 2005

^{xiii} Miller S, Shevell M, Patenaude Y, Poulin C, and Gorman A (2000): Septo-optic dysplasia plus: a spectrum of malformations of cortical development. **Neurology** 54:1701-1703.