

Pennsylvania Autism Assessment and Diagnosis

Expert Work Group Supporting Quality Diagnostic Practices for Persons with Suspected Autism Spectrum Disorder

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February 1, 2007

Pennsylvania has been working hard to develop quality Autism Spectrum Disorder services. In 2003, Estelle Richman, Secretary of the Pennsylvania Department of Public Welfare, created the *Autism Task Force* while was charged with developing plans for new systems for individuals living with Autism and their families. As a member of this Autism Task Force and in particular a member of the Educational Committee, we made recommendations to improve the professionals working with Autism Spectrum Disorder persons and their families and the services provided. (See: <http://www.dpw.state.pa.us/General/AboutDPW/SecretaryPublicWelfare/AutismTaskForce> for the complete executive summary including a response sent by myself and Dr. Stanley Greenspan).

In 2006, a collaboration between Department of Public Welfare and Department of Education of the commonwealth of Pennsylvania established the *Pennsylvania Autism Assessment and Diagnosis Expert Work Group* to define consistent and practical standards for evaluation and diagnosis of children with Autism Spectrum Disorder and provide structure and guidance for clinical teams to implement high quality evaluations of children with Autism. As a member of this expert Workgroup, my input especially focused on the importance of the family in the evaluation process. The Standards have been completed and will be available for publication soon.

In brief, recommendations of the work group are:

1. Appropriate evaluation **requires a multidisciplinary team approach** that examines **multiple domains of functioning** and provides a **profile of the child's strengths and weaknesses**.
2. The standard of care for autism **evaluation should include three stages**: a) conducting a medical and developmental history; b) completing a comprehensive developmental evaluation that addresses cognitive, language, adaptive, play, affective, sensory, behavioral and motor skills; and c) for uncertain cases, a specialized diagnostic evaluation, completed by a highly skilled clinician, using gold standard tools. Information from all stages of evaluation must be integrated into recommendations for intervention or educational programming.
3. The **standard of care must include providing results to parents in a cohesive, concise summary with supportive, ongoing counseling provided immediately following**.

4. In order to increase the capacity within Pennsylvania to provide appropriate diagnosis and assessment of children with autism, the protocol described in this report should be integrated into an ***interdisciplinary curriculum*** to train clinicians and educators. Training should occur at different levels of professional training, from undergraduate through continuing education. This training should also be integrated with training offered to professionals within the Department of Education.
5. Implementation of this protocol should include a system to **monitor and maintain quality of assessments through ongoing evaluations and training.**
6. All efforts should be overseen by an **advisory board that includes diverse representation from different disciplines and families of children with autism.**
7. In order to ensure that this protocol is implemented in an efficient and effective manner, **collaboration between the mental health/mental retardation and education systems and coordination of their resources must be improved** and should include developing a **shared standard for diagnosis and assessment.**
8. In order to create clinician incentives for appropriate diagnosis and assessment, **insurers must be required to reimburse for an interdisciplinary team** conducting this protocol as part of the assessment process.

We understand in ICDL that the Building Blocks of healthy development are a critical part of assessment and include a focus on functional development which includes the core capacities, individual neurobiological differences and family caregiver relationships. Pennsylvania has focused on the parents as experts of their child and a comprehensive assessment which is strongly interdisciplinary. Of particular note is Pennsylvania's establishment of three stages of assessment which will lead to more respectful and efficient assessments.

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