# AUTISM WORKGROUP POSITION PAPER

## A GUIDANCE DOCUMENT

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# FOREWORD

One of the primary responsibilities of the West Department of Education is to provide technical assistance resources that support successful learning experiences for children in West Virginia schools. We are pleased to provide this Guidance Document for Young Children with Autism as a resource to educators for the improvement of developmental appropriate practices for all young children with special needs. This document reflects current research and incorporates recommended classroom practices developed from expertise in the field.

The Guidance Document for Young Children with Autism is intended to facilitate the decision-making process regarding effective practices to improve services and student achievement in community settings and the classroom. Additionally, the document will help keep West Virginia at the forefront of educational practice.

Henry Marockie
State Superintendent of Schools

# EARLY CHILDHOOD AUTISM WORKGROUP POSITION PAPER

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## Introduction

Young children with autism (1) often present a considerable challenge to families and professionals. Because autism is a spectrum disorder, each child with autism has different needs. The variety of behavioral, educational, and developmental characteristics associated with autism makes the need for effective, individualized, comprehensive, intensive, and early intervention critical. The West Virginia Early Childhood Autism Task Force has developed this position paper to guide parents and professionals toward appropriate interventions and treatment.

## I. Diagnosis and Assessment

Because of the usefulness of early intervention for young children with autism, quick access to accurate diagnosis is essential. Diagnosis will be most accurate when it incorporates multiple methods of observation, including observations which may be obtained from multiple sources, in multiple settings. All areas of development must be considered because autism may present different combinations of developmental delays in each child. Observations by professionals and parents combined give the most complete report. It is important for families to receive a clear diagnosis in a timely fashion so they can access information, support, and services.

Thorough diagnosis and assessment take time, but the intense early intervention needs of children with autism cannot wait. Children are best served when appropriate intervention begins immediately upon recognition of their developmental delays; services should not be postponed until a consensus on a specific diagnosis is reached.

It is important to locate and identify children and families in need, or potentially in need, of services. The effort of actively trying to find these children can be made by the whole community, beginning with a child find that will identify all possible candidates. From there, a screening can identify children who need more thorough evaluation.

Diagnosis, establishment of eligibility for educational services, and on-going assessment should be conducted by trained diagnosticians, working within a trans-disciplinary team that includes parents. Interagency collaboration is essential to avoid duplication of screenings. With this practice, it is anticipated that stress to the family can be minimized. A commitment to cooperative collaboration among medical, educational, and community mental health professionals throughout the diagnostic process assists families in understanding the services available.

## II. Intervention Planning

After diagnosis, families have an immediate need to begin crafting a plan for education and treatment. Planning should begin as soon as possible, to meet the early intervention needs of the child and to help provide stability and support for the family. Access to information and knowledge of available treatment options help families make informed decisions.

### The Plan

Assessment is the starting point of the planning process. A comprehensive review of strengths and areas of need of the child's learning style and environment is useful to both parents and professionals in planning. The plan itself must be ***comprehensive***, ***individualized***, and ***functional***--that is, every one involved must see the plan as complete, correct, and meaningful, in both its long- and short-term goals. ***Flexibility*** is essential, and there should be an emphasis on the use of ***multiple strategies*** which should be driven by the child's strengths and changing needs, not by what services are available. Outcome-based ***evaluation*** strategies must be built into the plan, and the plan must be based on best practices in autism.

## The Process

It is of primary importance that planning be firmly ***focused on the family***. Children with autism present significant challenges in family life, and overwhelming family stress erodes family well-being. Children's families are by far their most important resource, and any useful planning appreciates this. Plans must be easily understood by families and free of obscure professional jargon. The planning process focuses on the family and its priorities, values, and resources. The process integrates all aspects of the family's life, moving beyond single issues such as educational or behavioral concerns, as these are never successfully addressed in isolation. Perhaps most importantly, the planning process considers and respects the family's hopes and dreams.

***A single coordinated plan serves child and family needs more effectively than many independent ones***. Agencies involved in the planning process must ensure that the plan has the input of a variety of disciplines and that there is smooth interagency coordination. Because developmental progress is unpredictable, effective on-going planning by all or part of the team should occur quite frequently; meetings should be of a frequency and duration based on need and not on a pre-set schedule. Meetings should be seen as opportunities for sharing information and considering its effect on the current program delivery, rather than as contractual obligations.

## III. Services

Effective services for young children with autism are based on empirically validated procedures. Research has shown that the critical component of the successful autism program is ***intensity***. An intensive intervention would provide for 15 to 40 hours of direct instruction per week. There must be a high adult-to-child ratio in the instructional setting which provides many opportunities for one-to-one or one-to-two interaction, especially during the early stages of intervention. The need for intervention continues year-round and extends into the home environment, so an effective program will involve the family and include plans for programming during school breaks and vacations. A classroom in which a child with autism is able to slip unattended into his own autistic world will not serve that child; nor will a program that provides only a few hours of direct, one-to-one instruction or therapy per week. Additionally, a child who has an excellent classroom program will only succeed if that program is supported by family involvement outside class time, and if that program does not disappear during the summer school vacation.

Every program must be individualized to meet the strengths and needs of the individual child. However, certain elements are common to all useful programs for young children with autism. Programs must provide direct instruction in core skills, including attention to environment, imitation of others, comprehension and use of language, appropriate play with toys, and social interaction with peers. They must offer highly structured and predictable routines within a schedule that is natural and logical and that gives appropriate opportunities for choice. Activities must be functional, helpful with peer interaction, appropriate to the child's environment, and supportive of full and active participation. Included also must be survival skills for transition and a functional approach to challenging behaviors. Finally, all services must take into account the unique sensory, medical, and cognitive issues of a child with autism. (2)

## IV. Training

Traditional professional training models have neglected description of the characteristics of autism; consequently, many individuals who find themselves working with children have inadequate training. Children with autism learn in ways that are significantly different from the learning styles of children with other disabilities. Training specific to the education of children with autism is essential. The most useful training is on-going, interdisciplinary, and includes all people with whom the child comes into contact: family, educators, community members, administrators, specialists, and service personnel, (e.g., bus drivers, volunteers).

## V. Evaluation

Included in any plan to deliver services, intervention, or education to young autistic children must be an effective system of evaluation. To give services of any description without evaluating whether those services are working for the child is irresponsible and potentially harmful.

Evaluation is an ***ongoing*** process, and must be conducted ***frequently*** to be useful. It should be ***systematic*** and ***thorough***. When methods of evaluation and data collection are ***consistent*** across agencies and over time, the findings are transferrable, can be used for program design, and can inform decisions at both the individual and the systems level. Feedback from evaluation must be used for ***program revision***, and should also be available to, and utilized by, policy-makers, agencies, and organizations. Such feedback broadens the knowledge base and makes more effective the constant revision of state programs and policies to best meet the needs of children and families.

Evaluation should be ***both objective and subjective.*** Teams must ensure that decisions regarding potential effectiveness of programs are not based on impressions alone; additionally, quantitative data should not be consulted alone when impressions appear to dispute those data.

Effective evaluation and data collection are ***family-centered***, based on the child's needs and the family's needs, and adapted to the environment. The assumption that the family is incapable of accurate data collection should never be made; nor should the opposite mistake be made of requiring impossible levels of data recording. It should be clear to everyone exactly what is being evaluated and why. Data should be analyzed and channeled back into program revision in a timely fashion. Thorough evaluation will not stop at this point but will also include issues of family satisfaction and quality of life.

1. The definition of autism used in this paper is that of the American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders (4th ed.) (1994). Washington: A.P.A.

2. This list has been adapted from Dawson, G., & Osterling, J. (1997) Early Intervention in Autism. In M.J. Guralnick (Ed.), The Effectiveness of Early Intervention: Second Generation Research. Baltimore: Brooks.

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