

Autism: Collaborative Perspectives in Education

Immanuel Hitipeuw

Abstract: Autism is the continuum of impairments. Children with autism show intellectual, social, emotional, and language or communication disorders. Collaboration is an important aspect in delivering education/intervention for children. Professionals have to have knowledge and skill related to autism and have to team up with parents in dealing with the disorder. The unique profile of the individual with autism calls for emphasis in the areas of communication skills, social-emotional, behavioral, and sensory regulation, and communication. Pre-identification of the children may help teachers and parents to make decisions whether the child needs a referral or not. In this case, Indonesia needs to make more political will in order to implement autism education in various setting to address immediate needs of the children before the problem becomes more complicated.

Key words: autism, collaboration, education.

Autism is one of the impairments that may not be commonly known by most of us, unlike other familiar impairments such as blindness, deafness, mental retardation, or orthopedical handicap. One important thing for the educators and professionals to do is to make our people aware of autism. A few months ago, one parent came to the department of Curriculum and Instructional Technology at IKIP Malang, one of whose programs

Immanuel Hitipeuw is an lecturer at the Special Education Program, Department of Curriculum and Instructional Technology, IKIP MALANG. This article is edited by Utami Widiati.

is special education. Unfortunately, at the time, the department couldn't give much information to accommodate the parent's need. From this experience, it is wise to start collecting information on autism and presenting it among educators who might meet parents whose children are autistic.

Another experience is when one of the faculty members from another department talked about his autistic son. This colleague looked confused about which professionals' suggestions he should follow to take care of his son's problems because there was no similar treatment among professionals, and even one professional tried to claim that other professionals' suggestions were not appropriate.

Therefore, as noted above, the objectives of this article are to explain briefly who autistic children are and what causes autistic, and to explore the assessment, identification and referral, curriculum, instruction and plan implementation, program characteristics, and training components. Special educational needs in Indonesia will be proposed at the end of this paper. The paper was based on the literature study that highlights collaborative perspectives in dealing with the education of the autistic children. Much information presented in this article was also obtained from internet at the Department of Education, State of California, the U.S.

WHO ARE AUTISTIC CHILDREN?

Children with autism are those marked by severe impairment of intellectual, social, and emotional functioning (Heward, 1996). Similarly, Wing and Gould (1979) in Wing's Triad of Impairments in Autism describe such children as having impairments in: (1) social; (2) language and communication; (3) thought and behavior.

Leo Kanner (in Costin and Draguns, 1989), American child psychiatrist, was the first person who identified the condition of autism in the children he observed, and he called the condition as infantile autism because the condition begins at the early years of infants. Since then, experts have studied and identified autism more deeply to make the symptoms more observable. Widerstrom et al. (1991) describe the classic symptoms of infantile autism as follow: (1) onset at birth or before age 2 after apparently normal development; (2) inappropriate social interactions with parents, other adults, and other children; (3) severely impaired commu-

nicative ability; (4) delayed cognitive development; (5) inability to make eye contact; (6) self-stimulating behaviors; (7) compulsive behaviors and inability to tolerate changes in routines and environments; (8) extreme distress for no discernible reason; (9) hyperactivity or hypoactivity often together with atypical sleep patterns; (10) difficulty in processing auditory stimuli, seeming not to hear certain sounds and overreacting to others by placing hands over ears; (12) apparent insensitivity to pain.

The symptoms have similarities with pervasive developmental disorder (Comer, 1992) that unfold at a later age, which results in severe delays of language, cognition, and social development. Therefore, autism is actually a particular kind of pervasive developmental disorder (APA, 1987).

One important thing is that children with autism may vary in the impairments. Some children may have good ability in oral language, while some other children may not have the ability. This condition makes autism as the continuum of impairments.

CAUSES OF AUTISM

Leading professional Dr. Bruno Bettelheim (Turnbull and Turnbull, 1990) mentioned that autism was caused by the stress created by parental attitudes and feelings. In response to the stress, he advocated 'parentectomy', institutionalizing the child to replace parents with institutional staff and professionals considered more competent and caring.

By contrast, a recent and precise cause of autism is unknown, but it almost certainly is of biological or organic origin (Rutter and Schopler, and Smith in Heward, 1996). Jordan and Powell (1995) state that at the level of biology there may be a number of different 'causes' that lead to the particular dysfunction in the brain. Genetic factors, brain chemical abnormalities on the baby may also become causes of autism. Moreover, certain illness in the mother may have damaged the developing fetus or there may have been anoxia or damage at birth. Jordan and Powell conclude that all of these different causes may have a common effect at the psychological level that results in the same psychological deficit that defines autism. But again this diagnosis is just to make sense of the defining features and explain why they co-occur.

ASSESSMENT

A comprehensive assessment and evaluation is needed to set the foundation for the overall quality and appropriateness of final recommendations in developing a program for the education of the child and for the needs of his or her family. Assessment has to be done as ongoing processes in order to gain accurate information to achieve high outcomes. Accurate assessment determines the success of an individualized early intervention and education program. Therefore, a developmental assessment is needed not only to identify the child's strengths and needs from which realistic teaching objectives are designed, but also to establish a baseline against which measures of progress can be made. More important, preintervention assessment data, when interpreted by experienced professionals and educators and shared with parents, will shape parents' expectations about treatment offered by the team.

Possibly mental retardation or learning difficulties may accompany the diagnosis of autism; and the diagnosis the child has can create stress among the child's parents when receiving the diagnosis, and may complicate the task of professionals in communicating developmental information and in discussing relevant information needed by parents. Professionals' responsibility is to share the information with parents to reach a mutual and realistic expectation of instructional outcomes as well as an understanding of alternative approaches. Turnbull and Turnbull (1990) give some suggestions that should inspire professionals in how to explain the disability diagnosis to families. These suggestions focus on parents as important persons that should be involved and know exactly who their own child is. The suggestions the professionals should do may include providing full and honest information about the condition of the child; repeating the information in many different ways and at many different times; trying to tell both parents at the same time; encouraging parents to ask questions; avoiding using educational or medical jargon as much as possible, and explaining those terms that must be used; presenting a balanced perspective—discuss possible positive outcomes as well as limitations; avoiding a patronizing or condescending attitude; encouraging parents to join a support group or introducing them to a family who is coping successfully with a son or daughter who has similar exceptionality; realizing the parents will need time to consider the diagnosis; setting up another conference; allowing parents time to express their feelings and

accepting of those feelings and understanding parents who may respond with displaced anger, but the attack is on the diagnosis, not you, and if parents respond with anger avoiding being defensive but continue to be supportive and accepting; discussing how to tell brothers and sisters and other family members; suggesting reading materials and other resources; assuring families that you will be available as a resource to them in the future. All these suggestions may not be needed for certain parents; in other words, professionals have to be sensitive in giving clarifications.

Collaborative aspects in comprehensive assessment can be seen through involving parents actively in the assessment process to assure that any assessment is reflective of the child's functioning within the family setting or from the parent's perspective.

Aspects in assessment which will be covered may differ as a result of an individual's age, developmental level, diagnosis, and areas of need. The aspects may include skills or activities in areas such as cognition, social and emotion, motor, self-help and independent living, communication, pre-academic and academic skills, play/leisure-time activities, community-based skills, and behavior.

Methods of assessment are individualized based on age, developmental level, diagnosis, and areas of need. Methods may include standardized tools, interview, observation, documentation, review of record and history of the client. Multiple setting, family, medical record and symptoms have to be covered by those methods in order to get comprehensive assessment results.

From this perspective, an assessment means a big task that can be achieved by team in order to reach the goal of the child.

IDENTIFICATION AND REFERRAL

Sharing among professionals is a must if we want to succeed in providing services or helping children with autism. Parent-professional partnerships add to the strength of effective service delivery systems and intervention plans. The child is best understood in the context of the family environment. Adjustments to this environment are the key to educational, behavioral, or adaptational changes in the child. Thus, the agents of change, including teachers, service providers, and community members extend to the family and other key individuals in the child's world. Collaborative process is needed in order to assist families in understanding

autism. Parents are encouraged to be full partners in the collaborative process.

McIntyre (1989) developed an inventory to observe children suspected having autistic disorder. This inventory was developed from various sources. The inventory (for all items see *The Behavior Management Handbook: Setting up Effective behavior Management Systems* 1989, by T. McIntyre) is important for teachers and parents in making decision whether the child needs referral to get further evaluation and assessment or not. So, this inventory functions as a pre-identification. Each item has its own characteristic describing behavior or learning pattern of autism. Children may not need to have all characteristics to be suspected having autistic disorder. The content of items shows that autistic disorder is a continuum, also shows behaviors of the child's parents. For example, some children may have normal intelligence, excellent motor and manual ability, hyperactivity, echolalia, or may hum or sing at perfect pitch, and so on, but some other children may have different characteristics such as quiet—passive—inattentive attitude, lack of creativity, even autism, and so on. While items relating to parents, they may have high level of intellectual ability and achievement, and may display rationality, objectivity, politeness, dignity, and seriousness, being humorless, introvert, and so on. The items are so simple to be used by teachers or parents, but to get the comprehensive results we still need other means to make a decision.

CURRICULUM, INSTRUCTION, AND PLAN IMPLEMENTATION

Specific problems that children with autism have require some adaptations and modifications to access the core curriculum. Modifications are needed as a basis for effective program planning. For young children, curriculum and interventions are defined by developmental stages and milestones and are outlined in the family plan. Curriculum design needs to reflect the unique learning styles and abilities of each child. Access to curriculum is dependent upon assessment results, method of instruction, learning style and learning materials, an environment which supports maximum learning, appropriate objectives, criteria for evaluation, selection of curricula, coordination of program across settings, and staff background and experience.

In order to respond with the continuum of the impairments, instruction and environment must be selected, adapted, and modified to allow the

child to demonstrate progress according to the standard measures identified by the curriculum and family plan and/or individualized educational plan. This can be accomplished by emphasis on the child's strengths and by addressing the areas that most interfere with learning (e.g., hyper/hypo-sensitivity to sensory processing - tactile, auditory, or visual).

Some characteristics of programs in areas such as social engagement, language, coping, and reduction of difficult behaviors that show growth in the results are (1) applied behavioral analysis, (2) a functional behavioral analysis approach, (3) the intervention, (4) positive behaviors, (5) replacement behaviors are used (e.g., substitute a simple acceptable behavior when a child begins to tantrum), (6) an individualized approach, (7) several intervention methods, (8) no single approach is likely to be right for every child, (9) the child is watched to see what interventions work, (10) the developmental curriculum, (11) the child's level of development is analyzed, (12) activities are planned at the child's level; (13) the curriculum is language-and communication-intensive, (14) socialization and play are actively stimulated, (15) only functional and meaningful tasks are used, (16) parent training and family support are used, (17) education about options for intervention is provided, (18) training is culturally acceptable to individual families, (20) collaboration of all team members is used, (21) transitional support is provided when the child leaves one program and moves to the next, (22) integration of research and practice is used, (23) follow-up of children with autism as they grow older is conducted, and so on.

Influences of environment are of great importance in dealing with autistic children. A variety of environmental and situational factors influence the behavior of all children and adolescents. Because these variables may have even greater significance for students with autism, a conscious effort must be made to carefully analyze the student and his or her environment as an ongoing component of the instructional process.

The physical environmental considerations should be taken into account by the team when implementing the individualized educational plan and family plan. The following considerations are (1) physical layout of the classroom with visually clear areas and boundaries; (2) selected work areas that best lend themselves to that being taught; (3) boundaries needed by the student; (4) specific schedules that allow the student to anticipate and predict activities; (5) individual work systems that convey what work

is to be done; how much work is to be done; how the student will know when he/she is finished; what happens after the work is completed; (6) visual organization of instruction to allow the individual to use the visual learning modality, which is often stronger than auditory; and (7) routines that allow the student to carry out the task in a systematic and consistent manner.

Medical and neurological consequences of autism prevent these children from learning in the usual way. The continuum of impairments creates the difficulty in developing educational or intervention programs for children with autism. Therefore the key characteristics that must be addressed include, but are not limited to, the following (1) disturbance in socialization; (2) inability to spontaneously model behaviors and deficits in observational learning; (3) repetitive and self-stimulatory behaviors; (4) other maladaptive behaviors, including aggression, self-abuse, excessive isolation, repetitive and ritualistic behaviors; (5) disturbances of attention; (6) deficits in all forms of communication, limited self-help skills; and (7) sensory hyper-and hypo-sensitivity.

In planning appropriate educational and intervention programs that meet the unique needs of students with autism, it is vital to use information and assessment data from many reliable resources. The assessment will yield current levels of functioning. Although all domains need to be considered, the unique profile of the individual with autism calls for emphasis in the areas of communication skills, social-emotional, behavioral, and sensory regulation.

PROGRAM CHARACTERISTICS

The program will differ from child to child because of the uniqueness of the autistic disorder. Program has to have a structured, collaborative effort as determined by the individualized educational plan (IEP), and family plan's team process to meet the individual and family needs.

Because of the symptoms, professionals and educators begin an appropriate intervention/education by thirty months. Teaching objectives are comprehensive and the child is given opportunities to generalize learned behaviors. Individual differences must be recognized in determining program intensity. Characteristics of effective programs may include the following (1) founded on the techniques of research-based methods and curricula; (2) clearly defined and have entrance and exit criteria; (3) su-

pervised by staff trained to understand the implications of autism; (4) inclusive of parents; (5) conducted in a variety of settings, (6) consistent across environments; (7) designed to allow the child to transition to settings or activities which promote more independent functioning; and (8) staffed to provide sufficient support to allow the individual to demonstrate progress.

Positive outcomes are a direct result of intensity and consistency of intervention across home, school, and community environments. The range of options can be expanded through interagency collaboration.

Agencies and parents identify programmatic needs based on the individual's assessment information. Goals and objectives are established in priority areas according to assessment findings, covering the child's strengths and needs and including child and family/parent priorities and needs, skills with functional outcomes, defined criteria for changing program components, and all domains relevant to the child's age and developmental level which may include motor skills, academic functioning, generalization, and maintenance of skills. In addition, specification of necessary service and program supports are identified; agencies responsible for services and/or program delivery are identified; the number of days of service in the calendar year is considered; specific identification of frequency and duration of services is made; service options and related services considered are specifically identified in writing; and procedures for promoting generalization and maintenance of skills are made.

The instructional setting and environment are determined in the IFSP, IPP, and/or IEP and are based on a comprehensive assessment that includes evaluation of potential environments and individual needs. Setting options need to be age-appropriate and may include combinations through non-public schools/agencies, community-based programs, district/county-operated special education programs, district special education settings and classrooms, general education settings and classrooms, home-based programs; or any combination of the above. So, the options are continuum in giving appropriate services.

Actual number of hours and days are determined based on the assessment and recommendation of an interdisciplinary team. Days and hours are determined by age, individual goals, and objectives of the child. The number of school days per year is defined by the team.

TRAINING COMPONENTS

Professionals, educators and other personnel have to have knowledge and skills necessary to deliver services. Knowledge preparation may include initial and ongoing training and support for personnel and families. Individuals who plan and provide training should disseminate information on training opportunities to parents, professionals, and agencies in the spirit of collaboration.

Educational personnel may have a wide variety of training needs that can be met in a variety of ways such as professional consultation, demonstration teaching, planned presentations and trainings at in-service sessions, workshops, and professional conferences, and attendance at university classes.

Needed Knowledge and Skills

The problems of autism need careful treatment. Service providers have to make sure that all personnels who work with the children have the following knowledge and skills to best meet their students' needs. They should be familiar with a variety of assessment methods, use assessment information to design interventions, apply positive behavioral management techniques during assessment and instruction, have knowledge of strategies to improve communication skills, have knowledge of techniques to improve social interaction, have knowledge of accommodations and interventions related to sensory differences, be aware of current legal issues affecting services to children with autism, and understand differences in the learning profile of children with autism. By these knowledge and skills we can expect the persons who will work with the child will be helpful.

Areas and Topics for Training

Training can be tailored to meet the needs of individuals within a service area or special education local plan area. Following are some selected areas and topics for training such as accommodation for sensory difference, adapting curriculum, assessment and evaluation procedures, augmentative/alternative communication, charting pupil progress, classroom organization or management, characteristics of different intervention approaches/methods, collaborative planning and teaching, current legal

issues, current research, data-based decision making, developmental assessment, discrete trial training, effective teaching strategies, e.g., visual strategies, functional analysis of behavior, parent-professional collaboration; positive behavioral interventions; role of play in program planning and implementation, strategies to improve social interaction, transitions, and so on. Through these topics the trainees will be competent and have broad perspectives.

SPECIAL EDUCATION NEEDS IN INDONESIA

Supports from Indonesian Government for special needs education are far from what special educators and parents of exceptional children expect. Most special schools' personnel conduct their instruction traditionally, whereas methods and strategies in teaching exceptional children have been developed highly to accommodate such children in various levels of integrated setting; and the goal is to make success for all disabled persons in pursuing their education. Moreover, most of these schools are located in big cities such as Jakarta, Bandung, Jogja, Surabaya, Medan and Denpasar, which are difficult to be reached by most students who live in remote areas.

The schools for autism are so limited and located only in some big cities such as Jakarta, Bandung, Jogja and Surabaya, and run by private agencies. The education offered by agencies in those cities is limited and may not include parents' training. Meanwhile, the 1945 constitution and Law of Educational System No. 2/1989 provide for the right of every citizen to education. However, the number of children with disabilities receiving an education is so few (Brohier, 1998), even Departmen Pendidikan dan Kebudayaan (Indonesian Ministry of Education and Culture) does not recognize autism in its national curriculum. This indicates the government may not pay much attention to the special needs of education.

In fact, integrated education for disabled persons, especially for the blind, was introduced and promoted in 1979 by the decree of Minister of Education and Culture no. 0222/0/1979. However, those in the field seem not ready to accept such children and then parents and their children with disabilities have difficulties in pursuing their education in regular settings.

Furthermore, Indonesian government in the international forum, represented by Minister of Social Welfare, signed the UN-ESCAP *Proclamation on the Full Participation and Equality of People with Disabilities*

in the Asian and Pacific Region (Brohier, 1998). This forum and the next review meeting of the forum have produced some targets in education. The targets range from increasing the number of students with disabilities in formal and non-formal education to including those people in all policies, plan, and programs in order to ensure education for all. The targets also include an integrated component on special education in the curricula for regular teacher training.

Meanwhile, those special educators need to take actions by giving more information on exceptionalities, and make more parents and other related professionals involved in seminars, conferences or in organizations for exceptionalities. Specifically, curricula and other supports from government and communities that promotes the development of the education for autism will create more chances for autistic children to achieve the normal life. Our schools' system, also, needs to develop assessment data stored in the forms such as IEP, IFSP, and the like. Such forms need to be backed up with a formal regulation to help professionals how to collaborate with others and parents to accomplish children's goals.

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