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MENTAL RETARDATION IN YOUNG CHILDREN

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Vanessa is an 18-month-old girl whose physical appearance is readily associated with Down syndrome. The syndrome was identified shortly after her birth, and she began receiving physical therapy and intervention for feeding problems. A developmental specialist meets with her parents to help monitor her progress and discuss the ways they can enhance her development. Vanessa's parents have sought information about her disability from advocacy organizations, and have joined a support for parents of children with Down syndrome.

Keith is a handsome 3-year-old boy whose mother has become increasingly frustrated by his behavior. She describes him as "hyper", and says that he "talks like a baby", does not listen, refuses to comply with her requests, and has frequent tantrums. Keith insists on feeding himself with his fingers, and ignores her when she tells him to put on his pajamas.

Crystal is a pretty 4-year-old girl with good motor skills and a ready smile. Despite participating in an inclusion program and receiving speech language therapy twice per week since the age of 2 years, her progress has been slow. She expresses herself in short phrases and was only recently toilet trained. Her parents have begun to question the quality of her preschool services. They acknowledge being told previously that Crystal had a developmental delay, but say they had assumed that intervention would help her "catch up" to other children of her age.

All of these children have mental retardation. Although Vanessa is too young to be given a formal diagnosis of mental retardation, she functions well below age expectancy and has a syndrome commonly associated with mental retardation. Her parents know that when formally tested, she will probably be found to have mental retardation. Because they have a name for her condition and have learned a good deal about it, they realize that Vanessa will require special services and supports throughout her lifetime.

Keith and Crystal are more confusing to their families. Because both children have an attractive appearance and can run and jump like other children of their age, their families expect them to function like other children in all aspects of their lives. Keith's mental retardation was never identified. Crystal was evaluated at 2 years of age, and found to have "developmental delay".

When formal evaluation shows that Keith and Crystal have mild mental retardation, this information, including the diagnostic label of "mental retardation" is shared with their families. Keith's mother gains the understanding that he is functioning at an earlier developmental level and cannot meet her expectations for behavior and progress. As she learns to form more developmentally appropriate expectations, his behavior improves. Crystal's parents gradually realize that intervention will optimize her development, but is not likely to "cure" her delay.

Definition

Mental retardation involves limitations in intellectual functioning and adaptive behavior (skills of daily living). The Individuals with Disabilities Education Act (IDEA) defines mental retardation as "significantly subaverage general functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance" (NICHCY Disability Fact Sheet No. 8).

Causes

The causes of mental retardation include genetic factors (associated with such conditions as Down syndrome or Fragile X syndrome) and premature birth, which increases the risk of developmental problems, including mental retardation. Specific causes of mental retardation are most frequently found for children with IQs below 50. Children who should be scrutinized most carefully for a medical cause are those with an atypical appearance, those with motor difficulties, and any child who has lost previously acquired skills. There are many children with mental retardation for whom a specific cause cannot be found, but rapid progress in genetics and neuroimaging may clarify the cause in the future.

IDENTIFICATION OF MENTAL RETARDATION

Intelligence Testing

Mental retardation is primarily determined by a child's performance on a standardized intelligence test. Intelligence tests are individually administered by psychologists trained in cognitive assessment. So that the tests are administered the same way for all examinees, test manuals specify exactly how test instructions must be worded, and how materials are presented to the child. For example, one test may specify that puzzle pieces should be handed to the child one by one. Another test requires presenting puzzle pieces in small stacks. These carefully specified variations reflect differences in developmental demands for the child.

Intelligence tests present many activities that are new to a child, and have not been previously taught. By presenting novel tasks (unfamiliar tasks that have not been practiced), the tests are measuring whether, when given standard instructions, the child can understand ("catch on" to) what is expected and organize herself to carry out the task.

Assessment of Adaptive Behavior

A diagnosis of mental retardation is based on deficits in adaptive behavior as well as significantly subaverage intelligence. Adaptive behavior refers to skills of daily living: dressing, feeding, bathing, toileting, communicating, and interacting with other people. Information is provided by someone who knows the child well. In young children there is a strong correlation between adaptive behavior and intelligence. The reason for this is that, as young children acquire new skills of daily living, they must "catch on" to what is expected and organize themselves to achieve task goals. In older individuals, skills of daily living are apt to have been trained and practiced so frequently that there are minimal demands for "catching on" to something new.

The Vineland Adaptive Behavior Scales are often used to measure adaptive behavior. Because Vineland standard scores tend to be inflated for young children with mental retardation (which could result in denial of services), practitioners include age equivalents in their reports.

Classification Ranges

Children are considered to have mental retardation if they function over two standard deviations below the mean of an intelligence test. Although practices vary, a correction for prematurity is generally made until the child is 2 years old. All intelligence tests have a mean of 100, and most have a standard deviation of 15 or 16. The standard deviation is used to classify mental retardation by levels of severity. For tests with a standard deviation of 15, classification ranges for mental retardation are mild (IQ 55-69), moderate (IQ 40-54), severe (IQ 25-39), and profound (below 25). Over 80% of individuals with mental retardation have mild mental retardation. An IQ between 70 and 84 indicates functioning within the borderline range of intelligence. A child with borderline intelligence is considered to be a slow learner, but does not have mental retardation. Sometimes intervention resources, though much needed, are less available for such a child.

In its 1992 and 2002 definitions of mental retardation, the American Association on Mental Retardation has prioritized intensities of supports, rather than IQ-based classification ranges, in planning intervention for individuals with mental retardation. Classification ranges continue to be used, however, because of their diagnostic usefulness, predictive value, and research applications. A young child with mild mental retardation will function very differently, currently and in the future, from a child with severe mental retardation.

Prediction Based on Early Assessment

Developmental testing during infancy is useful for identifying current needs, but is not very predictive of later cognitive ability. This is because infant tests measure motor and sensory-motor skills. Motor ability

has little relationship to intelligence. Once cognition can be measured, when a child with typical development is about 15 to 24 months of age, results of early testing begin to be more predictive of later functioning. It is at this age that abilities based on mental representation can begin to be assessed. The abilities include understanding and use of words, problem solving, deferred imitation, categorization, and recognition of similarities and differences. Prediction is less accurate for children with behavioral issues and problems of relatedness that may affect their ability to respond to the demands of early testing.

Many children who have mental retardation during early childhood, especially those with IQs below 50, will continue to have mental retardation, and to need special services, when they are older. These children will develop more slowly than children with IQs above 50, and will reach earlier plateaus (stages or mental ages at which more advanced cognitive development is not expected). Some children with mental retardation show improvement over time. For all young children with mental retardation, developmental follow-up is essential.

CHARACTERISTICS OF YOUNG CHILDREN WITH MENTAL RETARDATION

Dispelling Myths about Mental Retardation

Sometimes people think that children do not have mental retardation because they are physically attractive, have good motor skills, or show special competence in specific areas. These beliefs are incorrect. Although syndromes affect the appearance of some children with mental retardation, the majority cannot be identified by their physical features. Most children with mental retardation have good motor skills. During early childhood, they walk, run, balance, and jump just like other children.

Although many children with mental retardation function below age expectancy in all aspects of development, some have areas of better functioning. This is often true of children with concurrent autism spectrum disorders. Many of these children are good at memorizing letters, numbers, shapes, and colors. Because rote memorization does not require abstract conceptualization and reasoning, these "splinter skills" (isolated areas of better functioning) do not correlate well with intelligence.

Functioning Below Age Expectancy

Children with mental retardation function well below age expectancy. In developing expectations for progress and behavior, it is useful to base those expectations on mental age, rather than chronological age. For example, a 4-year-old with typical development can use full sentences to communicate ("I want to go to Grandma's house"). A 4-year-old with mild mental retardation functions more like a 2½-year-old, and may speak in brief phrases ("Grandma house"). A 4-year-old with typical development can dress independently. A 4-year-old with severe mental retardation, who functions more like a 16-month-old, may be able to pull off socks, but is apt to need help removing and putting on other clothing. A useful guideline is that children with mild, moderate,

severe, and profound mental retardation function at approximately 2/3, 1/2, 1/3, and below 1/3 of their chronological ages, respectively.

Behavioral Characteristics

In addition to functioning well below age expectancy, young children with mental retardation exhibit subtle differences in behavior when compared to age peers with typical development. The differences can be observed at home and in preschool classrooms and clinical situations.

Young children with mental retardation show less curiosity than other children. They engage in less exploration directed toward discovering the function of objects. They are apt to handle toys and other objects in general, rather than specific, ways. They spend more time holding objects in their hands, touching them nonspecifically, sliding them across a surface, throwing them, or dropping them onto the floor.

Young children with mental retardation tend to get stuck in earlier developmental patterns. Even when they have acquired more advanced skills, they may need prompting and encouragement to use the skills. They are apt to be more passive and reliant on adult support than other children, and to take less initiative for problem solving. They lack cognitive flexibility and have trouble "switching set". For example, a child with mental retardation may be able to complete a simple inset formboard in a standard presentation. If the formboard is rotated, he may not relate to the new spatial orientation and may try unsuccessfully to place the insets in their original positions.

Learning Characteristics

Young children with mental retardation learn more slowly than other children. Their rate of progress depends on the degree of mental retardation. They are also more likely to forget what they have learned. New skills must be reviewed and practiced in order to be maintained. The children do not easily generalize. They may not apply what they have learned to new situations because they do not recognize the similarity between the original learning context and the new context.

REASONS FOR IDENTIFYING AND LABELING MENTAL RETARDATION

Use of the term "mental retardation" is controversial, especially for young children. In educational settings, children functioning well below age expectancy can often obtain services without a label of "mental retardation". Depending on local guidelines, the terms "child with special needs" "preschool child with a disability", or "learning disability" are sometimes used. The term "mental retardation" is most apt to be used in clinical settings where diagnostic precision is a priority.

The term "developmental delay", rather than "mental retardation", is generally preferred for children under 3 years of age. Most children tested before age 3, who do not achieve standard scores above 50 on a developmental test, will be found to have mental retardation in subsequent intelligence testing. Because the term "developmental delay" is somewhat misleading and implies that a child will "catch up", many practitioners

tell the parents of children with significant early delays (standard scores of less than 50) that test results would indicate mental retardation in older children. This helps families begin to formulate realistic expectations for the children.

Identification of mental retardation can explain failure to meet expected developmental milestones, or a slow rate of progress despite appropriate intervention services. Mental retardation can also help to explain behavior problems. Because most children with mental retardation have an attractive physical appearance and good motor skills, their mental retardation is not suspected. The children's inability to do what others ask them to do is interpreted as noncompliance or willful misbehavior.

Other reasons for identifying mental retardation are to obtain supplemental security income and other entitlements for children. The term "mental retardation" can result in a medical search for a cause and can lead their parents to relevant literature, support groups, and advocacy organizations. Use of the term helps to set parameters and expectations for intervention.

INTERVENTION

Early intervention can optimize the development of young children with mental retardation. The children who can benefit most are those with mild mental retardation. Specialized preschools or inclusion programs are appropriate if the classroom pace and expectations are consistent with the children's slower learning rates. Speech language therapy, occupational therapy, and itinerant teacher services can be helpful if the goal is to address specific deficits (for example, inadequate vocabulary or fine motor coordination problems going beyond what can be explained by mental retardation). Young children with more significant degrees of mental retardation need intervention programs providing a good deal of adult support and an emphasis on self-care and socialization. Developmental therapies can be helpful if they address specific problems (for example, feeding, swallowing, or need for augmentative communication or use of adaptive equipment). Therapies should be carefully monitored for ongoing efficacy. In teaching new skills, it is helpful to think about characteristics of mental retardation in young children: slow learning, forgetting, and poor generalization.

Expectations about what intervention can accomplish should be realistic. The goal of intervention should be to maximize potential, rather than to "cure" the mental retardation. Parents, teachers, administrators, and service providers should be comfortable with the idea that more services, or greater service intensities, are not necessarily best for the child.

Concurrent Conditions

Many young children with mental retardation have other developmental problems. Concurrent conditions may include associated medical conditions such as seizures, sensory or motor deficits, or cerebral palsy; other developmental disabilities (for example, autism spectrum disorders); and/or mental health problems (for example, attachment disorders, mood disorders, or reactions to severe psychosocial stressors). In planning intervention for such children it is important to recognize

and address the mental retardation as well as the other conditions. If this is not done, responses to intervention may be disappointing.

CONCLUSION

By identifying cognitive limitations, obtaining or providing appropriate intervention as soon as possible, and formulating realistic expectations for progress and behavior, families and early childhood professionals can optimize developmental outcomes for young children with mental retardation.

RESOURCES

American Association on Mental Retardation (800) 424-3688. www.aamr.org

National Dissemination Center for Children with Disabilities. (800) 695-0285. www.nichcy.org

Smith, R. (1993). *Children with Mental Retardation: A Parents' Guide.* Bethesda, MD: Woodbine House.

The Arc of the United States. (301) 565-3842.
www.thearc.org

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