The Role of Etiology in the Education of Children with Mental Retardation

Abstract

The specific etiology of the child's mental retardation currently plays little role in special education services. After documenting the inattention to etiology in the field of special education, the present paper examines the behavioural effects of two common etiologies of mental retardation: Down syndrome and fragile X syndrome. For each of these disorders, etiology-specific approaches to intervention are suggested. The paper concludes with an evaluation of the appropriate role of the child's etiology for intervening with children with mental retardation.

Résumé

L'étiologie de l'arriération mentale d'un enfant revêt actuellement peu d'importance dans les services d'éducation spécialisée. Après avoir illustré le peu de cas que l'onfait de l'étiologie dans le domaine de l'éducation spécialisée, l'auteur de cet article analyse les effets de deux étiologies communes de l'arriération mentale sur le comportement: le syndrome de Down et le syndrome de l'X fragile. Pour chacun de ces dérèglements, on propose des méthodes d'intervention propres à l'étiologie. L'article se termine par une évaluation du rôle de l'étiologie de l'enfant pour intervenir auprès des enfants atteints d'arriération mentale.

In science and probably in the world at large, there are two kinds of people: lumpers and splitters. Lumpers consist of those persons who address a variety of related problems using a single approach, whereas splitters tackle different problems using different techniques. Obviously, which strategy is preferred relates to the problem of interest, to the effectiveness of answer required, and, maybe ultimately, to the personal tastes and inclinations of the individual problem-solver.

In the education of children with mental retardation, too, there are lumpers and splitters. Specifically, there are those who lump together for educational services all children with mental retardation. Their prevailing view is that, regardless of the cause of the child's retardation, all children with mental retardation are essentially similar, requiring only different amounts of services to succeed in a variety of educational environments (Rowitz, 1988).

In contrast, splitters begin by noting that mental retardation currently has 300 known causes and that many of these etiologies demonstrate etiology-specific behavioural characteristics (Burack, Hodapp, & Zigler, 1988; 1990). As a result, splitters argue, interventions focused on different etiologies might most effectively promote development in children with mental retardation (Gibson, 1991; Hodapp & Dykens, 1991).

This tension between lumpers and splitters is the focus of the present article. After briefly overviewing the inattention to etiology in the field of special education, we argue the etiology-based (or splitter) position by detailing patterns of behaviour differing in the two most common etiologies of mental retardation: Down syndrome and fragile X syndrome. We then suggest interventions that might help each group, before ending with an evaluation of the appropriate role of etiology in the delivery of special education services.

Etiology in Current Educational Services

In most school settings, etiology currently plays no role in the services received by children with mental retardation. Granted, the child's specific etiology is sometimes (not always) known to educational personnel. Similarly, all children receive Individualized Education Plans (IEPs) that are tailored to the child's specific strengths and weaknesses but the child's specific etiology is rarely if ever considered in intervention efforts. Etiologically-based strengths and weaknesses, developmental trajectories, and styles of learning are seldom incorporated into IEPs, nor do most educational personnel evaluate interventions in terms of the child's particular type of mental retardation.

This inattention to etiology is also seen in the leading journals of special education. Consider, for example, the two journals *Exceptional Children* and the *Journal of Special Education*. Throughout the entire period from 1985 through 1991, there is not a single research article in either journal that is focused on children with one or another type of mental retardation. Many articles examine behaviour in children with mild or moderate mental retardation, or the effects of different intervention techniques on such children, but research subjects are never divided by etiology.

This overview of research articles reflects the general feeling that persons interested in the behaviour of children with mental retardation need not

concern themselves with the etiology of the child's condition. Kahn (1988) summarizes this perspective in a recent book review when he asserts that "Most special educators do not believe that etiology is pertinent to their function. Certainly etiology is relevant for physicians, audiologists, and other medically-oriented personnel, but this book is aimed primarily at special education teachers" (p. 550).

The inattention to etiology is also congruent with the move during recent years to avoid deleterious effects of labeling by using terms that are as generic as possible. As Rowitz (1988) notes, "During the 1970s, the early years of the developmental disabilities legislation, there was an attempt to maintain the differentiations among the specific developmental disabilities" (p. 2). But later, "The specific diagnostic groupings were dropped and replaced with a generic definition of developmental disabilities. All forms of physical and mental disabilities of a severe nature were combined to create a generic definition" (p. 2). Legislation began to focus on persons with developmental disabilities as a single undifferentiated group, with blind, deaf, epileptic, and otherwise impaired individuals included along with the various forms of mental retardation. Increasingly forgotten was the possibility that children with different types of mental retardation might have different behavioural profiles and respond best to different types of intervention.

Effects of Etiology on Behaviour

But do children with different forms of mental retardation actually behave differently? From increasing numbers of studies, the answer appears to be "yes," that children with different types of mental retardation do demonstrate etiologically specific behavioural characteristics.

The examples of fragile X syndrome versus Down syndrome

To illustrate etiologic specificity, we need only review recent behavioural findings on Down syndrome and fragile X syndrome. As the first and second most prevalent causes, respectively, of mental retardation, these two syndromes are both very common, but they differ radically in their histories and research traditions. Down syndrome is the oldest known cause of mental retardation, with a long and distinguished history of behavioural work. The syndrome is the subject of several excellent research summaries: David Gibson's *Down Syndrome: The Psychology of Mongolism* (1978) comes first to mind, although other summaries are also available (Cicchetti & Beeghly, 1990; Gibson, 1991).

In contrast, fragile X syndrome was only discovered in the late 1960s. Only at that time did researchers begin to unravel the genetics of a prevalent, X-linked disorder primarily affecting males, but for which females could be

either affected or unaffected carriers (Opitz, 1986). As a result of its recent discovery, behavioural work on fragile X syndrome dates only to the early 1980s and, even today, many aspects of fragile X behavioural functioning remain unknown (Dykens & Leckman, 1990).

The two disorders differ too in their profiles of cognitive and adaptive behaviour. Compare, for example, performances of each group on the Kaufman Assessment Battery for Children (K-ABC) (Kaufman & Kaufman, 1983). The K-ABC is a psychometric instrument based on the distinction between sequential (i.e., serial or bit-by-bit) versus simultaneous (i.e., holistic) processing proposed by J.P. Das and his colleagues (Das, Kirby, & Jarman, 1975). Males with fragile X syndrome perform especially poorly on the K-ABC's domain of sequential processing relative to their abilities in simultaneous processing and in achievement (Dykens, Hodapp, & Leckman, 1987; Hodapp et al., in press). In contrast, children with Down syndrome show equal performance on sequential and simultaneous processing (Pueschel, Gallagher, Zartler, & Pezzullo, 1987). Furthermore, the single K-ABC subtest upon which males with fragile X syndrome show their weakest performance is Hand Movements, a set of tasks involving the repetition of a series of hand gestures displayed by the examiner. In contrast, for children with Down syndrome, Hand Movements is among the strongest of all K-ABC subtests (Hodapp et al., in press; Pueschel et al., 1987).

The two disorders also show etiology-specific patterns in both adaptive and maladaptive functioning. On the *Vineland Adaptive Behaviour Scales* (Sparrow, Balla, & Cicchetti, 1984), for example, males with fragile X syndrome show particular strengths in daily living skills (washing, grooming, toileting) and lower performance on communication and socialization (Dykens, Hodapp, & Leckman, 1989). In contrast, children with Down syndrome show relative strengths in socialization abilities, although they too show weaknesses incommunication (particularly in expressive communication) (Dykens, Hodapp, & Evans, 1992). In maladaptive behaviours, males with fragile X syndrome appear particularly prone to hyperactivity and, to a lesser extent, to autism and autistic-like behaviours (Dykens & Leckman, 1990), whereas children with Down syndrome have been characterized as affectively stable and as showing relatively low rates of psychopathology (cf. Bregman, 1991). In cognitive, adaptive, and maladaptive behaviours, then, children with fragile X syndrome differ from those with Down syndrome.

In addition to differences in behavioural profiles, the two etiologies also show characteristic trajectories of development. Boys with fragile X syndrome develop at a near-steady (albeit slowed) rate until early puberty, at which time development virtually halts for these children. This finding of slowed development beginning in the early pubertal years has now been noted in intellectual functioning (Dykens et al., 1989; Lachiewicz et al., 1987) and, most recently, in adaptive behaviour (Dykens, Hodapp, Ort, & Leckman, in press). This pattern of steady development until a plateauing during the late middle-childhood or early adolescent period seems unique to fragile X syndrome.

Children with Down syndrome experience different, but also unusual, changes in developmental rates as they get older. These children show spurts and lags in development, periods of relatively rapid advances followed by several-year periods during which few new skills emerge. The University of Calgary's David Gibson (1966) first identified this spurt-lag pattern in Down syndrome performance on IQ tests, but such patterns appear also in the development of grammar (Fowler, 1988) and of adaptive behaviour (Dykens, Hodapp, & Evans, 1992). Fowler's (1988) recent work on grammar is most instructive in this regard, as she finds that children with Down syndrome progress in grammar at normal or near-normal rates of development from approximately 4 to 7 1/2 years of age, but then demonstrate a total plateau from 7 1/2 to 10 1/2 years (after which grammatical development resumes). As her study featured longitudinal examinations of children varying in abilities, Fowler was also able to show that children with higher versus lower IQs (i.e., above and below IO 50) both showed the Down syndrome plateau during this middle childhood period, indicating that such slowing was due to age-related factors. While it remains unclear why children with Down syndrome show such spurts and lags, these changes in rate of development differ from those seen in boys with fragile X syndrome and may have implications for intervention efforts.

Implications for intervention

Given the inattention to etiology by most special educators, few formal intervention programs are yet based on etiology-specific behavioural strengths and weaknesses. The findings above, however, imply some preliminary strategies.

In the area of cognition, the fact that boys with fragile X syndrome are relatively less impaired on simultaneous processing may provide more effective intervention approaches. As Dykens and Leckman (1990) note, these children may respond well to a teaching strategy that begins by emphasizing the overall meaning of a task before breaking down the task into its component parts. As simultaneous processing often involves visual-spatial abilities, the use of maps, graphs, diagrams, and pictures may be especially helpful for boys with fragile X syndrome.

This approach may lend itself to particular interventions within the school setting. For example, it may be easier for these children to learn to read using whole-word versus phonetic reading methods (Scharfenaker, Hickman, & Braden, 1992). Braden's (1989) Logo Reading System, which uses logos from fast food and grocery store chains to encourage word recognition, may be particularly helpful for these children. More visuo-spatial, holistic approaches to math and other school subjects may also be beneficial to boys with fragile X syndrome.

As children with Down syndrome show no particular strength or weakness in simultaneous relative to sequential processing, for them the "simultaneous" style of introducing information may not be as critical. The strength of these children in the Hand Movements subtest is, however, of potential benefit. Several researchers are currently examining the use of gestural signs as a way for children with and without retardation to enter into the language system (Abrahamson, Cavallo, & McCluer, 1985). This strategy, which combines signs with words, appears reasonable given the strength of children with Down syndrome in the imitation of hand movements; this technique may not be as successful with boys with fragile X syndrome (Hodapp & Dykens, 1991).

The timing of interventions, too, might be related to the etiology of retardation. As Fowler (1988) notes, children with Down syndrome advance in grammar at near-normal rates from 4 to 7 1/2, show plateaus from 7 1/2 to 10 1/2, then develop again during the early teen years. Interventions aimed at teaching grammar might thus concentrate on the times of rapid development for these children; interventions during periods of plateau may be less successful. Based on this type of finding, Gibson (1991) proposes that children with Down syndrome be considered separate in intervention efforts from children with other types of mental retardation.

Issues and Problems

In proposing that the child's etiology of mental retardation be considered an important component in intervention efforts, we acknowledge that several important issues remain. Three issues, in particular, deserve notice.

First, not every etiological group differs from every other group in every aspect of behaviour. Given the limited number of cognitive, adaptive, and maladaptive profiles, there will necessarily be some degree of cross-etiologic consistency in behavioural strengths and weaknesses. In addition, certain aspects of development will be the same for all children, regardless of etiology. For example, with only a few rare exceptions, all children with mental retardation (regardless of etiology) appear to progress in order through Piagetian and other universal sequences of development. There are thus both etiologically specific and etiologically general aspects of behaviour. The sophisticated joining of these general and specific aspects of behaviour constitutes an important goal in any program of intervention (Hodapp & Dykens, 1991).

Second, there is variability within etiological groups (Pennington, O'Connor, & Sudhalter, 1991). For example, whereas children with Down syndrome – as a group – plateau in development during the 7 1/2 to 10 1/2 year period, our own cross-sectional findings in adaptive behaviour imply that some children may advance and others decline during this period (Dykens et al.,

1992). Not all children will follow the pattern of their etiological group to the same extent, and such variability also needs to be considered.

The third, and related, point is that etiology should be considered as simply one aspect of the child. Granted, the etiology of the child's mental retardation is an important personal characteristic. But information concerning the etiology of the retardation must be joined with specifics about the child's age, overall level of functioning, gender, interests, styles of learning and other individual characteristics to form an optimal strategy of intervention (Burack et al., 1990).

Still, even given these three caveats, etiology remains an important and undervalued aspect of the child that needs to be incorporated within any educational program. As we illustrate in our survey of fragile X and Down syndrome behavioural features, many aspects of behaviour do seem related to etiology. Similarly, most individuals within a particular etiological group show the group pattern, at least to some extent. Interventionists should take advantage of such "etiology-specific" behavioural information in the conceptualization of special education services.

Ultimately, then, while we are "splitters" in the issue of etiology's role in the education of children with mental retardation, our eventual goal is the lumping of biology and environment, a joining of the child's etiology-specific strengths-weaknesses, styles of learning, and trajectories of development to the interventions offered. Only by this joining of biology and environment can we best promote development in children with many different forms of mental retardation.

REFERENCES

- Abrahamson, A., Cavallo, M., & McCluer, J. (1985). Is the sign advantage a robust phenomenon? From gesture to language in two modalities. *Merrill-Palmer Quarterly*, 31, 177-209.
- Bregman, J. (1991). Current developments in the understanding of mental retardation:

 Part II. Psychopathology. *Journal of the American Academy of Child and Adolescent Psychiatry*, 30, 861-872.
- Braden, M. (1989). Logo reading system. Colorado Springs, CO: Author.
- Burack, J.A., Hodapp, R.M., & Zigler, E. (1988). Issues in the classification of mental retardation: Differentiating among organic etiologies. *Journal of Child Psy*chology and Psychiatry, 29, 765-779.
- Burack, J.A., Hodapp, R.M., & Zigler, E. (1990). Technical note: Toward a more precise understanding of mental retardation. *Journal of Child Psychology and Psychiatry*, 31, 471-475.

- Cicchetti, D., & Beeghly, M. (Eds.) (1990). Children with Down syndrome: A developmental perspective. New York: Cambridge University Press.
- Das, J.P., Kirby, J., & Jarman, R.F. (1975). Simultaneous and successive abilities: An alternative model for cognitive abilities. Psychological Bulletin, 82, 87-103.
- Dykens, E.M., Hodapp, R.M., & Evans, D.W. (1992). Profiles and development of adaptive behaviour in children with Down syndrome. Manuscript submitted for publication.
- Dykens, E.M., Hodapp, R.M., Ort, S., Finucane, B., Shapiro, L., & Leckman, J. (1989).

 The trajectory of cognitive development in males with fragile X syndrome.

 Journal of the American Academy of Child and Adolescent Psychiatry, 28, 422-428.
- Dykens, E.M., Hodapp, R.M., & Leckman, J.F. (1987). Strengths and weaknesses in the intellectual profiles of males with fragile X syndrome. American Journal of Mental Deficiency, 92, 234-236.
- Dykens, E.M., Hodapp, R.M., Ort, S.I., & Leckman, J.F. (in press). Trajectory of adaptive behaviour in males with fragile X syndrome. *Journal of Autism and Developmental Disorders*.
- Dykens, E.M., Hodapp, R.M., & Leckman, J.F. (1989). Adaptive and maladaptive functioning in fragile X males. Journal of the American Academy of Child and Adolescent Psychiatry, 28, 422-426.
- Dykens, E.M., & Leckman, J.F. (1990). Developmental issues in fragile X syndrome. In R.M. Hodapp, J.A. Burack, & E. Zigler (Eds.), Issues in the developmental approach to mental retardation (pp. 226-245). New York: Cambridge University Press.
- Fowler, A. (1988). Determinants of rate of language growth in children with Down syndrome. In L. Nadel (Ed.), The psychobiology of Down syndrome (pp. 302-328). Cambridge, MA: MIT Press.
- Gibson, D. (1966). Early developmental staging as a prophecy index in Down's syndrome. American Journal of Mental Deficiency, 70, 825-828.
- Gibson, D. (1978). Down syndrome: The psychology of mongolism. Cambridge, England: Cambridge University Press.
- Gibson, D. (1991). Down syndrome and cognitive enhancement: Not like the others. In K. Marfo (Ed.), Early intervention in transition: Current perspectives on programs for handicapped children (pp. 61-90). New York: Praeger Publishers.
- Hodapp, R.M., & Dykens, E.M. (1991). Toward an etiology-specific strategy of early intervention for handicapped children. In K. Marfo (Ed.), Early intervention in transition: Current perspectives on programs for handicapped children (pp. 41-60). New York: Praeger Publishers.
- Hodapp, R.M., Leckman, J.F., Dykens, E.M., Sparrow, S., Zelinsky, D., & Ort, S.I. (in press). K-ABC profiles in children with fragile X syndrome, Down Syndrome, and nonspecific mental retardation. American Journal on Mental Retardation.
- Kahn, J.V. (1988). Review of M. Sternlicht, Special education: A source book. American Journal on Mental Retardation, 92, 550-551.
- Kaufman, A.S., & Kaufman, N.L. (1983). Kaufman Assessment Battery for Children. Circle Pines, MN: American Guidance Service.
- Lachiewicz, A.M., Gullion, C., Spiridigliozzi, G., & Aylsworth, A. (1987). Declining IQs of young males with fragile X syndrome. American Journal on Mental Retardation, 92, 272-278.

- Opitz, J. (1986). Commentary: On the gates of hell and a most unusual gene. American Journal of Medical Genetics, Special issue: X-linked mental retardation, 23, 1-10.
- Pennington, B., O'Connor, R., & Sudhalter, V. (1991). Toward a neuropsychology of fragile X syndrome. In R.J. Hagerman & A.C. Silverman (Eds.), Fragile X syndrome: Diagnosis, treatment, and research (pp. 173-201). Baltimore: Johns Hopkins Press.
- Pueschel, S.M., Gallagher, P.L., Zartler, A.S., & Pezzullo, J.C. (1987). Cognitive and learning processes in children with Down syndrome. Research in Developmental Disabilities, 8, 21-37.
- Rowitz, L. (1988). Homogenization of deviance. Mental Retardation, 26, 1-3.
- Scharfenaker, S., Hickman, L., & Braden, M. (1991). An integrated approach to intervention. In R.J. Hagerman & A.C. Silverman (Eds.), Fragile X syndrome: Diagnosis, treatment, research (pp. 327-372). Baltimore: Johns Hopkins Press.
- Sparrow, S., Balla, D., & Cicchetti, D. (1984). Vineland Adaptive Behaviour Scales.

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