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Child Health and Parental Stress in School-Age Children With a Preschool Diagnosis of Developmental Delay

Richard I. Webster, MBBS, MSc, FRACP, Annette Majnemer, PhD, OT, Robert W. Platt, PhD, and Michael I. Shevell, MD, CM, FRCPC

Chronic disorders are known to have a wide-ranging impact on overall health and family dynamics. The objective of this study was to assess child health and well-being and parental stress in a cohort of school-age children diagnosed before school entry with either global developmental delay or developmental language impairment. In total, 65 children with preschool developmental delay were assessed at school age (mean ± SD age: 7.3 ± 0.7 years) with the Child Health Questionnaire and Parenting Stress Index, with a mean interval between assessment of 3.9 years. Almost all children who completed testing (60/62) continued to show developmental impairments across domains. On the Child Health Questionnaire, children showed the greatest impairment on the mental health scale (median *z* score: –0.9). The median Child Health Questionnaire psychosocial health score (40.7) was almost 1 SD below established normative values ($P < .001$). More than 40% of parents had a Parenting Stress Index above the 85th percentile (clinically significant parenting stress). Using multiple linear regression analysis, high levels of parenting stress were best predicted by a child's Child Health Questionnaire psychosocial health score ($r^2 = 0.49$, $P < .001$). Thus, 4 years after a preschool-age diagnosis of developmental delay, poor psychosocial health was a common comorbidity. Almost half the parents showed clinically significant levels of parenting stress. There is a need to both recognize and provide ongoing social and emotional support for young children diagnosed with developmental disability and their families.

Keywords: developmental delay; child health; parental stress

Studies evaluating the outcomes associated with a preschool diagnosis of developmental disability have concentrated on the child's later development and function. Instruments evaluating developmental and functional outcomes identify limitations in everyday activities but have a limited capacity to assess the health and well-being of children with developmental disability. Furthermore, they are not designed to assess the impact of a child's disability on parental stress. Given that there is evidence that the quality of family relationships has an effect on a child's development[1] and that parenting stress has adverse effects on a child's behavior,[2] assessments of parental stress, as well as measures of a child's quality of life, are important to fully characterize the impact of developmental disability.

Measures of health-related quality of life attempt to capture the multidimensional impact of a disease or disability on a child's well-being.[3-5] Such measures reflect not only a child's functioning (physical status) but also a child's well-being (psychosocial status).[3] Although it is expected that developmental disability will impose functional limitations on a child's life, a child's psychosocial well-being is influenced by psychological, family, and societal factors that are potentially independent of the actual level of function.

Having a child with a developmental disability has a considerable impact on the family. The parents often have considerably greater demands placed on their time compared to parents of typically developing children.[6] Elevated levels of parenting stress are frequently reported in the families of children with developmental disability.[7] Although developmental disability is strongly associated with higher levels of parental stress, cognitive function is a relatively poor predictor of parental stress. Stress levels have been found to be associated most strongly with

From the Departments of Neurology/Neurosurgery (RIW, AM, MIS), Pediatrics (AM, RWP, MIS), and Epidemiology and Biostatistics (RWP), School of Physical and Occupational Therapy (AM), McGill University, Montreal, Quebec, Canada, and the Children's Hospital Educational Research Institute, Children's Hospital at Westmead, Westmead, Sydney, Australia (RIW).

Address correspondence to: Dr Michael Shevell, Room A-514, Montreal Children's Hospital, 2300 Tupper St, Montreal, Qc H3H 1P3, Canada; e-mail: michael.shevell@muhc.mcgill.ca.

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measures of family functioning, behavioral characteristics of the child, and the child's intrinsic personal/social skills.[7,8] Despite these observations, relatively little is known objectively regarding health-related quality of life and parental stress in the setting of early childhood neurodevelopmental disabilities.

A cohort of 169 preschool-aged children diagnosed with either global developmental delay or developmental language impairment underwent initial assessment at Montreal Children's Hospital as part of a prospective study investigating the etiologic yield in children with developmental delay.[9-11] Children diagnosed with either global developmental delay or developmental language impairment were reevaluated almost 4 years after initial diagnosis so as to ascertain the outcomes associated with a preschool-age diagnosis of developmental delay.[12-14] This study had 3 specific aims: (1) to document the health-related quality of life and parental stress levels of these children and families, (2) to identify developmental and extrinsic factors that were predictive of a child's quality of life and parental stress levels, and (3) to assess whether quality of life and parental stress differed in children with a preschool diagnosis of either global developmental delay or developmental language impairment.

Methods

Population

A cohort of preschool children originally recruited between June 1, 1996, and November 30, 1997, and diagnosed with developmental delay (either developmental language impairment or global developmental delay) was systematically reassessed when they were between 7 and 8 years of age. These children were drawn from a group of 224 consecutive preschool children (aged <5 years) referred to the Montreal Children's Hospital for initial assessment of developmental delay.[9,11,15]

Between January 2000 and July 2002, follow-up was attempted on all children from this original cohort aged between 7 and 8 years with a preschool diagnosis of either global developmental delay or developmental language impairment. Letters were sent to the parents of all children followed by telephone contact. Informed consent was obtained before study participation. Approval was obtained from the hospital's institutional review board before commencing the study.

Measures

The Child Health Questionnaire Parent Form 50 was used as a measure of a child's overall health and well-being.[3] The Child Health Questionnaire Parent Form is a 50-item questionnaire administered to parents of children aged between 5 and 18 years that aims to assess a child's physical and psychosocial well-being. The Child Health Questionnaire Parent Form consists of 14 subscales highlighting factors that affect a child's health. The *z* scores for these measures were calculated using normative data from a representative US population-derived sample. Summary scores for Physical and Psychosocial Health were derived by aggregating the weighted scores of these scales (excluding the latter 3 scales) as per the Child Health Questionnaire manual. A standard score (mean 50, SD 10) was calculated for Physical and Psychosocial Health.

The Parental Stress Index Short Form was used as a measure of parental stress.[16] The Parental Stress Index Short Form, designed to assess the level of stress in the parent-child system, is a 36-item parent-completed questionnaire composed of 3 subscales: Parental Distress, Parent-Child Dysfunctional Interaction, and the Difficult Child. On the basis of these 3 measures, a Total Stress score is calculated that reflects the overall level of parenting stress. The Parental Stress Index Short Form scores of parents who met criteria for Defensive Responding were not included in our analysis due to this limitation as per the measure's manual. Percentile scores are reported for the Total Stress score and the subscales of the Parental Stress Index Short Form. Normative data were derived from a large US sample.[16]

The full-scale Battelle Developmental Inventory was used to assess motor, cognitive, social, adaptive, and language outcomes for this sample.[17] The Battelle Developmental Inventory is a standardized instrument (mean 100, standard deviation 15) that assesses development in 5 separate domains with excellent, well-established psychometric properties.[18] Published normative values have a "floor" effect such that all children whose standard scores fall below 65 (–2.3 standard deviations) score 65.

The Vineland Adaptive Behavioural Scale was used as a measure of a child's functional capability, in the domains of communication, socialization, and activities of daily living.[19] The Vineland Adaptive Behavioural Scale was administered to the parents of each child. It has excellent psychometric properties within the age range of the children assessed in our study.

Results of the developmental and functional measures in these children have been reported previously.[12,13,20]

Statistical Analysis

Statistical analysis was performed using SPSS Version 11.5 software.[21] Mean scores with standard deviations are reported for normally distributed data, and median scores with interquartile ranges are reported for data that were not normally distributed. Student *t* tests were used to compare the scores on the Parental Stress Index Short Form and Child Health Questionnaire Parent Form between French- and

Table 1. Comparison of Children From Original Preschool Cohort of Global Developmental Delay and Developmental Language Impairment Whose Parents Completed the Parental Stress Index Short Form and Child Health Questionnaire Parent Form and Those Who Did Not

	Completing Questionnaire (n = 65)	Not Completing Questionnaire (n = 104)	*P* Value
Initial age, y, at evaluation, mean ± SD	3.4 ± 1.0	3.3 ± 1.2	.47
Age of parental concern, y, mean ± SD	2.0 ± 0.9	2.0 ± 1.0	.97
Boys, n (%)	47/65 (72)	82/104 (79)	.33
Moderate to severe delay, n (%)	35/65 (54)	59/104 (57)	.71
Etiology determined, n (%)	14/65 (22)	31/104 (30)	.24

English-speaking populations and between children with global developmental delay and developmental language impairment. The Child Health Questionnaire Parent Form and Parental Stress Index Short Form scores of children with global developmental delay or developmental language impairment were compared with expected normative data using a 1-sample sign test because these scores showed a markedly skewed distribution. Gender distributions and socioeconomic status were compared using the chi-square statistic. The correlation between child health from the Child Health Questionnaire Parent Form, parental stress, and developmental and functional measures was assessed using Kendall's tau-b statistic because of the need to correlate data that were not normally distributed. A stepwise multiple linear regression model was used to identify developmental and functional measures that were predictive of the Psychosocial Health score on the Child Health Questionnaire Parent Form and scores on the Parental Stress Index Short Form. For these analyses, the Battelle Developmental Inventory communication domain was omitted because only half of the children were assessed with this measure due to its lack of established validity as applied to French-speaking children.

Results

Group Characteristics

Ninety-one children (91/169; 54%) with a preschool-age diagnosis of developmental delay were recruited from the original cohort, but due to time constraints at the follow-up assessment, the parents of 65 of these families (34 global developmental delay, 31 developmental language impairment 65/91 [71%]) were administered the Child Health Questionnaire Parent Form and the Parental Stress Index Short Form. Compared to the original cohort of 169 children, there were no significant differences at preschool intake between the group of 65 children whose parents completed the questionnaires and those who did not (Table 1). Nor were there any significant differences between the 2 groups with regard to markers of parental socioeconomic status (maternal and paternal employment and highest level of educational achievement) for each parent. Thus, the sample presented herein appears to be representative of the original cohort.

Sixty-two children (62/65; 95%) were assessed with all 4 instruments (Vineland Adaptive Behavioural Scale, Battelle Developmental Inventory, Child Health Questionnaire Parent Form, and Parental Stress Index Short Form), 1 child was assessed with all instruments other than the Battelle Developmental Inventory, and the parents of 2 children completed the Parental Stress Index Short Form and Child Health Questionnaire Parent Form, but the Vineland Adaptive Behavioural Scale and Battelle Developmental Inventory were not administered. Twenty-five children (25/91; 27%) who were recruited for this study completed assessment with the Battelle Developmental Inventory and the Vineland Adaptive Behavioural Scale but did not undergo assessment with the Child Health Questionnaire Parent Form or Parental Stress Index Short Form. The mean scores for these 25 children were somewhat higher in all functional and developmental domains than those of the 63 children who completed assessment with the Child Health Questionnaire Parent Form and Parental Stress Index Short Form, although these differences did not reach statistical significance. One child (1/91) did not complete testing on any measure.

The mean age of the 65 children assessed with the Child Health Questionnaire Parent Form and Parental Stress Index Short Form at the time of their outcome assessment was 7.3 ± 0.7 years, and the mean interval between the children's initial diagnostic evaluation and follow-up assessments was 3.9 ± 0.9 years. Of the 63/65 (97%) children who underwent developmental (Battelle Developmental Index) and/or functional assessment (Vineland Adaptive Behavioural Scale), almost all (62/63; 98%) showed evidence of ongoing impairment (a score falling below the 3rd percentile) in at least 1 of the 5 developmental domains assessed (motor, cognitive, personal-social, communication, daily living), and the majority (52/63; 83%) were impaired in 2 or more developmental domains. The median Battelle Developmental Inventory standard scores (with 25th to 75th percentile range) were as follows: personal-social, 65.0 (65.0-81.0); adaptive, 65.0 (65.0-81.0); motor, 69.0 (65.0-87.0); communication, 65.0 (65.0-65.0); and cognitive, 65.0 (65.0-82.0). The mean (± SD) standard scores for the Vineland Adaptive Behavioural Scale domains were as follows: socialization, 78.1 ± 17.3;

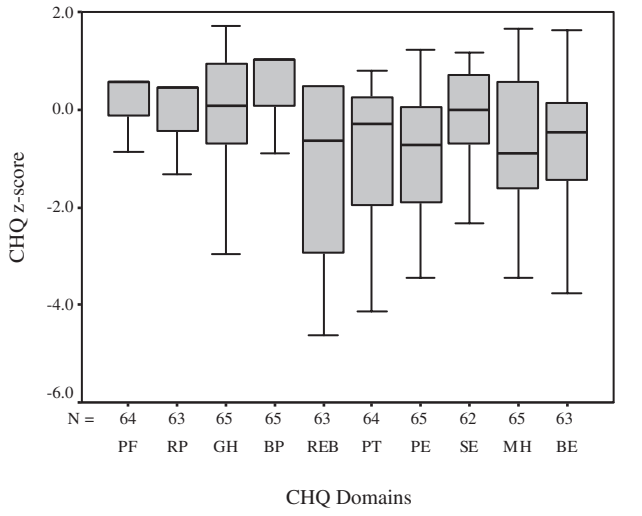

Figure 1. Median *z* scores for the Child Health Questionnaire (CHQ) Scales. The median *z* scores (solid lines) with the 25th to 75th percentile range (shaded boxes) and range without outliers (whiskers) for the separate scales of the Child Health Questionnaire are plotted compared to normative US data. PF indicates physical functioning; RP, role/social—Physical; GH, general health perceptions; BP, bodily pain; REB, role/social emotional/behavioral; PT, parental impact—time; PE, parental impact—emotional; SE, self-esteem; MH, mental health; BE, behavior.

daily living, 69.7 ± 21.6; and communication, 72.2 ± 20.4. Children with a preschool diagnosis of developmental language impairment showed significantly better performance than children with global developmental delay in all domains of the Vineland Adaptive Behavioural Scale and in the adaptive, motor, and cognitive domains of the Battelle Developmental Inventory.[20]

Health-Related Quality of Life

The Child Health Questionnaires were most often completed by the children's mothers (57/65; 88%). Sixty-one parents (61/65; 94%) completed all items on the Child Health Questionnaire Parent Form. The median *z* scores (with interquartile ranges) for Child Health Questionnaire Parent Form scales and the number of parents who completed each scale are shown in Figure 1. The *z* scores that were significantly below normative values were noted in the psychosocial weighted scales. By contrast, scores that were significantly above normative values were noted in the role/social limitations in the physical health scale (median *z* score = 0.45, $P = .001$), the physical functioning scale (median *z* score = 0.56, $P = .006$), and bodily pain and discomfort scale (median *z* score = 1.0, $P < .001$). Consistent with the above, the children's Psychosocial summary scores fell significantly below normative values (median 40.7, $P < .001$). By contrast, the children's Physical summary scores were significantly higher than normative values (median 55.0, $P = .005$).

Children with a preschool diagnosis of global developmental delay had lower scores than children with developmental language impairment on most psychosocial weighted scales (time impact on parents, emotional impact on parents, mental health, self-esteem), but these differences did not reach statistical significance. Median *z* scores on the physical health scales of the Child Health Questionnaire Parent Form for children with global developmental delay or developmental language impairment were identical for all scales other than the general health perceptions (median: global developmental delay 0.1, developmental language impairment 0.3). The median Psychosocial summary score was 39.7 for children with global developmental delay and 45.2 for children with developmental language impairment ($P = .15$), and the median Physical summary score was 53.2 for children with global developmental delay and 55.2 for children with developmental language impairment ($P = .35$). No significant differences were noted in either the Psychosocial Health summary score or the Physical Health summary score between children assessed as having a moderate or severe delay and those with a mild delay at the time of their initial preschool assessment.

Parental Stress

Sixty-five parents completed the Parental Stress Index Short Form. Most forms (58/65; 89%) were completed by the mother of the child. The responses of 11 parents (17%) met criteria for defensive responding, and these reports were not evaluated further as per standards established for interpretation of this evaluation. One of the remaining parents completed responses for only 2 domains of the Parental Stress Index Short Form, and so complete questionnaires were available for 53 parents. The mean scores for the separate domains of the Parental Stress Index Short Form are shown in Figure 2. Eighteen parents (18/54; 33%) had high scores (85th percentile or greater as established by the creators of this instrument) on the Parental Distress subscale, 25 parents (25/54; 46%) had high scores on the Parent-Child Dysfunctional Interaction subscale, and 23 parents (23/53; 43%) had high scores on the Difficult Child subscale. Overall, more than 40% of the parents (21/53; 42%) had Parental Stress Index Short Form total scores indicating that they were experiencing clinically significant elevated stress levels (greater than or equal to the 85th percentile). Sixteen parents of children initially assessed as having global developmental delay (16/30; 53%) reported clinically significant levels of total parenting stress compared with 8 parents (8/23; 35%) of children with a preschool-age diagnosis of developmental language impairment ($P = .38$). The parents of children assessed as having a moderate or severe delay at their preschool-age assessment were significantly more likely to report clinically significant levels of total parenting stress (odds ratio [OR]: 3.7; 95% confidence interval [CI]: 1.1-12.0) at outcome. Families whose fathers had

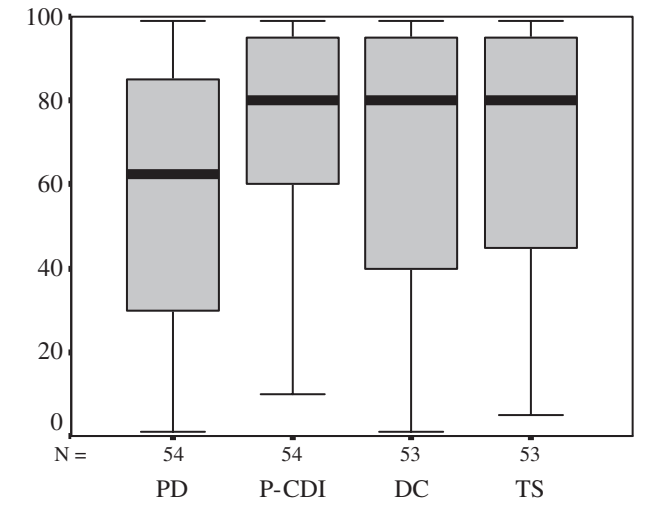

Figure 2. Distribution of percentile scores for the Parenting Stress Index. The median percentiles for individual domains of the Parental Stress Index Short Form (solid lines) with 25th to 75th percentile range (shaded boxes) and range (whiskers) without outliers for the separate scales of the Parental Stress Index Short Form are plotted compared to normative US data.[21] PD indicates parental distress; P-CDI, parent-child dysfunctional interaction; DC, difficult child; TS, total stress.

postsecondary education had significantly lower levels of parenting stress (mean Parental Stress Index Short Form total stress for families with fathers with post–high school education [71.6] vs mean stress for those without post–high school education [89.1], $P = .04$). Current parental employment status and maternal postsecondary education were not significantly associated with total parenting stress levels.

Predictors of Child and Family Well-Being

Correlations between functional (Battelle Developmental Inventory) and developmental (Vineland Adaptive Behavioural Scale) measures and Physical and Psychosocial summary scores (Child Health Questionnaire Parent Form) and Total Parental Stress are presented in Table 2. Child Health Questionnaire Parent Form psychosocial health scores correlated best with the personal-social scale scores on the Battelle Developmental Inventory. Physical health scores were most strongly correlated with the Vineland Adaptive Behavioural Scale communication and socialization scores, as well as motor scores on the Battelle Developmental Inventory. Parental stress levels correlated most strongly (and negatively) with a child's performance on the Battelle Developmental Inventory personal-social scale and with limitations in all domains of the Vineland Adaptive Behavioural Scale.

Using multiple linear regression analysis to examine whether scores on the Vineland Adaptive Behavioural Scale predicted a child's Child Health Questionnaire Parent Form psychosocial health score, performance on the socialization domain of the Vineland Adaptive Behavioural Scale was found to be significantly associated ($r^2 = 0.11$, $P = .01$). Using a similar procedure to look at the predictive value of the Battelle Developmental Inventory domains, the personal-social domain of the Battelle Developmental Inventory proved to be the best predictor of a child's Child Health Questionnaire Parent Form psychosocial health score ($r^2 = 0.21$, $P < .001$). When these scores were included in the regression model, other domains of the Vineland Adaptive Behavioural Scale and Battelle Developmental Inventory were no longer significant predictors of Child Health Questionnaire Parent Form psychosocial health scores.

A multiple linear regression model was used to investigate which child-related factors were most strongly predictive of total parental stress levels on the Parental Stress Index Short Form. A child's Psychosocial summary score on the Child Health Questionnaire Parent Form proved to be the single best predictor of Total Parental Stress ($r^2 = 0.49$, $P < .001$). Given that the Child Health Questionnaire Parent Form Psychosocial score is weighted toward 2 scales that reflect the impact of a child's disability on their parents (the parent impact—time and the parent impact—emotional), the multiple linear regression was repeated without the

Table 2. Correlations Between Functional (Vineland Adaptive Behavioural Scale) and Developmental Measures (Battelle Developmental Inventory) and Scores on the Child Health Questionnaire Parent Form and the Parental Stress Index Short Form (Total Stress)

	Child Health Questionnaire Parent Form Psychosocial Health Score	Child Health Questionnaire Parent Form Physical Health Score	Parental Stress Index (Total)—Raw Score
Vineland Adaptive Behavioural Scale—Communication	**.002**	**.001**	**.001**
Vineland Adaptive Behavioural Scale—Daily Living	**.02**	**.04**	**.002**
Vineland Adaptive Behavioural Scale—Socialization	**.002**	**.002**	**.001**
Battelle Developmental Inventory—Personal-Social	**<.001**	.10	**.001**
Battelle Developmental Inventory—Adaptive	.17	.51	.03
Battelle Developmental Inventory—Motor	.07	**.002**	**.04**
Battelle Developmental Inventory—Communication	.67	.21	.50
Battelle Developmental Inventory—Cognitive	**.006**	.83	**.01**

NOTE: Data presented as *P* values. The domain(s) showing the strongest correlation with child health scales or parental stress scales are highlighted in bold font.

inclusion of the Child Health Questionnaire Parent Form Psychosocial and Physical Health summary scores. When the model was evaluated without these variables, Total Parent Stress was predicted by a combination of a child's score on the Vineland Adaptive Behavioural Scale socialization domain and the Battelle Developmental Inventory personal-social scale ($r^2 = 0.24$, $P < .001$).

Discussion

A preschool-age diagnosis of developmental delay is associated with ongoing developmental and psychosocial morbidity. Almost 4 years after an initial diagnosis of developmental delay, the vast majority of children continued to show evidence of ongoing developmental disability. Measures of psychosocial health in these children fell significantly below normative values, and slightly more than 40% of the parents of these children reported total parenting stress levels that fell within the clinically significant range.

The Child Health Questionnaire Parent Form demonstrated that these children had significant problems in the areas of behavior and mental health. By way of contrast, the children's self-esteem did not differ significantly from normative data. However, in normal children, an ability to make comparative judgments about oneself develops at about 8 years of age,[22] and so the finding of a normal level of self-esteem in this group of children is not surprising.

The Child Health Questionnaire Parent Form incorporates 2 measures that address the impact on the family of a child's behavior, mental health, and learning abilities.[3] Parents reported significantly elevated levels of worry or concern as a result of their child's emotional well-being, behavior, or learning abilities and increased limitations on their time as a result of their child's health or behavior. These 2 variables receive a relatively high weighting on the Psychosocial summary score of the Child Health Questionnaire Parent Form. Given that these factors potentially increase parents' stress, the fact that the children's Psychosocial summary scores were predictive of the level of parental stress was not unexpected.

Clinically significant total parental stress levels were found in almost half of these parents. These levels of parental stress are very similar to those reported in another longitudinal study of children with developmental disability.[1] This study found that when their children were 10 years of age, approximately 40% of parents reported high levels of parenting stress.

These very high levels of parenting stress suggest that there is an ongoing need to support parents of children with developmental disability that extends well beyond the period immediately following diagnosis. Teaching these parents stress management strategies and providing adequate respite care and parent support groups opportunities may help them address some of the challenges associated with parenting a child with a developmental disability. These results also suggest the need for a programmatic approach to management of these diagnoses that incorporates sequential assessments of well-being and family others.

A child's socialization skills proved to be the strongest functional and developmental predictors of parental stress levels. These findings suggest that interventions that address difficulties in a child's socialization skills, so as to promote interaction and participation, may have a greater impact on a child's psychosocial health and parental stress levels than interventions in other areas. Although therapy for children with developmental disability has focused on areas such as communication skills and motor skills, improvements in these areas may not promote changes in a child's social skills, and more specific targeted intervention along these lines may be necessary.

We had originally hypothesized that children originally assessed as having isolated language impairment at their preschool-age assessment would have better overall health and lower levels of parental stress than children with global developmental delay. However, at outcome, although children with developmental language impairment had higher scores for almost all scales of the Child Health Questionnaire Parent Form and a marginally lower proportion of parents reported elevated levels of parenting stress, these differences did not reach statistical significance compared to the group with global developmental delay. This may reflect the fact that most children classified as having isolated language impairment at the time of the preschool-age assessment had evidence of impairments in other developmental domains; indeed, the majority met criteria for global developmental delay at outcome.[12]

Although a child's personal-social skills proved to be the best predictor in our study, this explained only about 25% of the variance in total parental stress levels. This study did not address particular behavioral characteristics of the child or measures of family relationships that have been shown to be predictive of parenting stress levels.[1] Higher levels of paternal education were significantly associated with lower levels of parenting stress, perhaps reflecting better competence or means of securing available resources.

Interventions for children with developmental disability have focused predominantly on the obvious functional disabilities and limitations that these children experience (speech/language therapy, occupational therapy). Evidence from this study suggests that the personal/social skills of children with developmental disability are strong predictors of child and family well-being. Although improvements in communication and motor skills may have secondary effects on a child's personal/social skills, there appears to be a continuing need for direct interventions that explicitly and specifically address the social and behavioral difficulties that children with a developmental disability experience. Furthermore, resources are explicitly needed to support families so as to improve coping and ease overall family burden.

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References

1. Hauser-Cram P, Warfield ME, Shonkoff JP, et al. Children with disabilities: a longitudinal study of child development and parent well-being. *Soc Res Child Devel*. 2001;66:1-126.
2. Baker BL, McIntyre LL, Blacher J, et al. Pre-school children with and without developmental delay: behaviour problems and parenting stress over time. *J Intell Dis Res*. 2003;47:217-230.
3. Landgraf JM, Abetz L, Ware JE. *The Child Health Questionnaire User's Manual*. Boston, MA: The Health Institute, New England Medical Centre; 1999.
4. Wallander JL, Schmitt M, Koot HM. Quality of life measurement in children and adolescents: issues, instruments, and applications. *J Clin Psych*. 2001;57:571-585.
5. Matza LS, Swensen AR, Flood EM, et al. Assessment of health-related quality of life in children: a review of conceptual, methodological, and regulatory issues. *Value Health*. 2004;7:79-92.
6. Beckman PJ. Comparison of mothers' and fathers' perceptions of the effect of young children with and without disabilities. *Am J Ment Retard*. 1991;95:585-595.
7. Johnston C, Hessl D, Blasey C, et al. Factors Associated with parenting stress in mothers of children with fragile X syndrome. *J Devel Behav Pediatr*. 2003;24:267-275.
8. Smith TB, Oliver MNI, Innocenti MS. Parenting stress in families of children with disabilities. *Am J Orthopsych*. 2001;71: 257-261.
9. Shevell MI, Majnemer A, Rosenbaum P, Abrahamowicz M. Etiologic yield of single domain developmental delay: a prospective study. *J Pediatr*. 2000;137:633-637.
10. Shevell MI, Majnemer A, Rosenbaum P, Abrahamowicz M. Etiologic yield of subspecialists' evaluation of young children with global developmental delay. *J Pediatr*. 2000;136:593-598.
11. Shevell MI, Majnemer A, Rosenbaum P, Abrahamowicz M. Etiologic determination of childhood developmental delay. *Brain Devel*. 2001;23:228-235.
12. Webster RI, Majnemer A, Platt RW, Shevell MI. The predictive value of a preschool diagnosis of developmental language impairment. *Neurology*. 2004;63:2327-2331.
13. Webster RI, Majnemer A, Platt RW, Shevell MI. Motor function at school age in children with a preschool diagnosis of developmental language impairment. *J Pediatr*. 2005;146:80-85.
14. Shevell M, Majnemer A, Platt RW, Webster R, Birnbaum R. Developmental and functional outcomes at school age of preschool children with global developmental delay. *J Child Neurol*. 2005;20:648-653.
15. Shevell MI, Majnemer A, Rosenbaum P, Abrahamowicz M. Profile of referrals for early childhood developmental delay to ambulatory subspecialty clinics. *J Child Neurol*. 2001;16:645-650.
16. Abidin RR. *Parenting Stress Index*. Lutz, FL: Psychological Assessment Resources; 1995.
17. Newborg J, Stock JR, Wnek L, et al. *Battelle Developmental Inventory*. Itasca, IL: Riverside Publishing; 1988.
18. Berls AT, McEwen IR. Battelle Developmental Inventory. *Phys Ther*. 1999;79:776-783.
19. Sparrow S, Balla DA, Cichetti DV. *Vineland Adaptive Behavior Scales Interview Edition*. Circle Pines, MN: American Guidance Service; 1984.
20. Shevell M, Majnemer A, Platt RW, Webster R, Birnbaum R. Developmental and functional outcomes in children with global developmental delay or developmental language impairment. *Dev Med Child Neurol*. 2005;47:678-683.
21. Statistical Package for Social Sciences (SPSS). Version 11.5. Chicago: SPSS, Inc; 2002.
22. Harter S. *The Construction of the Self: A Developmental Perspective*. New York, NY: Guilford; 1999.