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EARLY INTERVENTION COLLABORATIVE STUDY (EICS): LATE  
ADOLESCENCE

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**Comprehensive Final Report  
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**Early Intervention Collaborative Study (EICS) Phase IV: Late Adolescence**

**I. Introduction**

**A. Statement of the Problem**

Since 1985, the Early Intervention Collaborative Study (EICS) has investigated the development of over 150 children identified with early developmental delays or disabilities, and the adaptation of their families to the challenges of parenting a child with developmental disabilities (DD). We have also investigated the types, intensity and effects of therapeutic, social, health, and educational services received by children and their families. The current phase of this longitudinal study was designed to investigate both the health and development of these children during late adolescence and the challenges faced by their parents. Age 18 is a milestone in the lives of children and their families as traditionally, it marks the assent into adulthood, often accompanied by graduation for high school and moving away from home. Adolescents with disabilities, however, often continue to participate in the public school system beyond age 18 and also often continue to live with their parents or primary caregiver.

**B. Purpose, Scope and Methods**

The specific aim of this phase of EICS was to examine the social-emotional outcomes of adolescents with DD at age 18 (self-regulation relating to behavior, social interaction, and autonomy) and the well-being of their mothers and fathers (psychological well-being, psychological distress, and physical well-being). We examined adolescents' developmental trajectories as well as trajectories of parent well-being to determine core predictors and points of association. Mothers, fathers, and the adolescents themselves were interviewed separately and completed a set of questionnaires.

**C. Nature of the Findings**

Several critical findings emerged from the longitudinal analyses. First, children's behavior problems (from age 3 to age 18), displayed an increase through the early childhood and middle childhood years followed by a decrease over time. Girls, in comparison to boys, showed a greater increase in behavior problems over time. Children in better health (compared to those in poorer health) had fewer behavior problems at age 10 and showed a more rapid decline in behavior problems by age 18.

Second, children's self-reported peer relationships between ages 10 and 18 did not show a significant change. However, children with Down syndrome reported significantly higher peer acceptance scores at age 10 than children with other disabilities. Also, at age 10 mothers who had more supportive social support networks had children with higher perceived peer acceptance. These differences at age 10 continued throughout the adolescent period.

Third, in relation to changes in parenting stress from the child's entry to early intervention through age 18 years, mothers had greater changes in stress when children

exhibited higher levels of behavior problems. In contrast, fathers had a downturn in parenting stress when they reported experiencing greater confidence in their parenting.

Fourth, in relation to parents' depressive symptoms, on average both mothers and fathers had scores that were well under the clinical cut-off. For mothers, changes in depressive symptoms from when her child was ages 10 to 18 were related to dyadic cohesion (i.e., relationship with their spouse or partner). Mothers who reported higher levels of dyadic cohesion had decreases in depressive symptoms. In contrast, fathers showed increases in depressive symptoms when their family experienced more negative life events (i.e., challenging experiences not related to the child, such as losing a job). Thus, depressive symptoms appeared to be related to parents' relationships and events not directly related to the adolescent with a disability.

Analyses of cross-sectional data at age 18 pointed to the importance of adolescent behavior problems. Such problems served as a mediator of the relation between the mother-teen relationship and the teen's autonomy. For both mothers and fathers teen behavior problems related negatively to parent well-being. The caregiving burden was an added predictor of poorer well-being of mothers (not fathers), and social support added positively to well-being for both mothers and fathers.

## **II. Review of the Literature**

This study has been guided by an ecological perspective (Bronfenbrenner & Morris, 1998) in which children are considered to be embedded in multiple interacting systems: psychological, family, and peer. In particular, concerning the adolescent period, we have been guided by Lerner's (1991) model of person-context relations. To varying degrees, adolescents both select and affect the various contexts in which they develop (e.g., the peer group, employment settings) and these, in turn, influence the adolescent's development. "Goodness-of-fit" between the adolescent and the demands of the context is essential for optimal development (Lerner, 1992). This "fit" may be stretched or transformed during transitional points (i.e., times when systems may change in nature or composition). Age 18 is often a time of such transition for typically developing youth, but we know little about the experiences of adolescents with disabilities and their families during this age period (Hauser-Cram & Krauss, 2004).

In regards to the adolescents themselves, two areas of social-emotional development appear to be central to their well-being: behavior problems and peer acceptance. Children with disabilities are three to four times more likely to develop behavior problems (Tonge, 1999), and the rate of severe psychopathology in children with DD has been found to increase dramatically during adolescence (Borthwick-Duffy, 1994). Thus, although very few prospective studies exist, cross-sectional studies indicate that adolescence is a particularly vulnerable time for behavior problems of those with DD (Richardson, Koller, & Katz, 1985). Type of disability (Hodapp, 1998) and related skill deficits (Einfeld & Tonge, 1996) appear to affect the expression of problematic behavior. Although the family environment has been found to relate to behavior problems (Richardson et al., 1985), little is known about the extent to which family processes predict changes in behavior problems from early childhood through adolescence (Black, Molaison, & Smull, 1990).

The importance of peer relationships throughout childhood and adolescence is stressed in the developmental literature; such friendships help children advance both

cognitively and socially (Hartup, 1996). Children with DD often have deficits in peer interaction, generally due to deficits in social cognition (Leffert & Siperstein, 2002), although such deficits are more pronounced for those with certain disabilities (such as autism). In our prior longitudinal investigation of social skills from infancy through middle childhood in the EICS sample, we found that children with Down syndrome and those from more positive family relational environments had greater increases in social skills (Hauser-Cram et al., 2001), but little research exists on the role of families in peer acceptance during the adolescent period.

In relation to parents of adolescents, both parenting stress and depressive symptomatology appear to be central aspects of well-being. Wikler (1986) found that stress among parents of sons and daughters with disabilities is highest during the adolescent years. Zetlin and Turner's (1985) ethnographic study also revealed that parents of children with disabilities viewed the adolescent experience as more problematic than the early childhood period. Stress relating to parenting is multiply determined, however (Crnic & Low, 2002). As children with disabilities age, their behaviors are less well tolerated and they are less socially acceptable than younger children with disabilities whose atypical behaviors are less deviant than their age peers (Bristol, 1984; DeMyer & Goldberg, 1983). Further, the lack of community acceptance for adolescents with disabilities may translate into greater social isolation of their families and continued adherence to family routines followed throughout early and middle childhood that are different from those practiced by families of typically developing adolescents (Gallimore, Bernheimer, & Weisner, 1999). Being socially isolated and stuck in long-established family routines may dampen the confidence of mothers and fathers in the parenting role.

Although few longitudinal studies of parents of children with disabilities have examined changes in depression, Gowen et al. (1989) measured depression for mothers when their children were infants and toddlers. They found that maternal depression fluctuates over time. Drawing on aspects of social ecology theory, family systems theory, and family stress theory, three dimensions of the overall family ecology are likely to predict these changes in depression. First, negative life events have been found to lower reports of well-being in other studies of family adaptation (Sameroff, et al., 1987). Second, specific characteristics of the child such as caregiving needs and behavior problems, have been found to impact well-being among parents of young children with DD (Erickson & Upshur, 1989). Finally, aspects of the family environment such as specific dyadic relationships have been found to influence parent well-being (Floyd & Saitzyk, 1992). Thus, characteristics of both the child and the family are related to parent well-being.

### **III. Study Design and Methods:**

#### **A. Study Design**

The study is a continuation of a non-experimental, longitudinal investigation of a sample of children with early-identified disabilities and their families. Children and families have participated in this study since their entry into early intervention (EI) services during the child's infant or toddler years. Findings from the early childhood

phase of the study can be found in Shonkoff et al., (1992), and from the early-to-middle childhood phase in Hauser-Cram et al. (2001).

Participants were originally recruited from 29 community-based early intervention programs in Massachusetts and New Hampshire. Parents were asked to participate if their child had Down syndrome (and was no older than 12 months of age), motor impairment (and was no older than 24 months of age), or developmental delay of unknown etiology (and was no older than 24 months of age). The diagnosis of children with Down syndrome was confirmed by a review of the medical records. Children with motor impairment were selected to participate if they had evidence of abnormal muscle tone (hypotonia, hypertonia, or fluctuating tone) or a coordination deficit along with delayed or deviant motor development, with or without other delays. Children with developmental delays were selected to participate if they had evidence of delays in two or more areas of development with no established diagnosis or etiology that implied a specific diagnosis at the time of entry into EI.

### **B-C. Participants/ Sample Selection**

A total of 190 children and families were initially recruited into the study. Attrition has remained at 9-10% between data collection periods although the attrition between the last phase of this study (age 15) and the current phase (age 18) was lower than predicted (6%). At age 18 a total of 130 adolescents (55 % male) and families continued to participate. Some families (n= 9) did not continue to participate in this phase of the study; several families have moved without forwarding addresses or other means of contact (n= 6), and some children have died (n=3). The sample at age 18 consisted of the following groups based on the type of disability reported during the early intervention phase: 41 adolescents with Down syndrome, 49 with motor impairment, and 40 with developmental delay. About two thirds of the adolescents reported to live with two parents (76.2%). Only 18.5% of the adolescents were not receiving school services through an IEP or 504 plan. Marital status has changed in the last 3 years in 4.9% of the families. On average, the parents reported having some education beyond high school (Mean (SD)= 14.3 (2.4) years for mothers, and 13.4 (3.7) years for fathers), although parents reported a wide range of educational levels (from 8<sup>th</sup> grade to graduate school). The adolescents are predominately Euro-American (91.5%) (1.6% African-American, 3.9% Hispanic/Latino, and 3.2% Other). In relation to employment, 81.2% of fathers reported to be employed full-time, 40.8 % of mothers reported to be employed full-time, with 27.7% of mothers employed part time. Average family annual income was between \$45,000 and \$49,999.

### **D. Procedures/Instrument**

Data collection occurred primarily in participants' homes, although some fathers chose to be interviewed at their place of employment. Field staff members were trained to be reliable in data collection procedures and were blind to study hypotheses. Reliability checks were conducted throughout the data collection period. One staff member conducted a multidimensional cognitive and functional assessment with the adolescent. Other staff members interviewed the mother and father. A questionnaire booklet was left for the sibling (closest in age to the target adolescent) to complete.

A list of tests and measures and their psychometric properties can be found in Tables 1 and 2.

### **E. Analytic Approach**

For the longitudinal data analysis we employed hierarchical linear modeling (HLM) techniques (Raudenbush & Bryk, 2002). HLM techniques allowed us to test both time varying covariates and time-invariant factors as main effects, moderators, and mediators of both status and change. Based on the general linear model, we selected to employ hierarchical linear regression to test hypotheses related to cross-sectional data.

### **IV. Detailed Findings:**

A set of six hypotheses were examined during this study phase. Each hypothesis is listed below followed by a brief description of the results. Refer to Table 1 for a list of measures used in these analyses.

*Hypothesis 1. Changes in children's behavior problems from early childhood through adolescence will be predicted by characteristics of the child (type of disability, gender, health) and characteristics of the family system (parent health, parenting confidence) moderated by the child's level of cognitive development.*

This hypothesis was tested using hierarchical linear modeling (HLM). First, a level-1 analysis was conducted to find the appropriate functional form to represent individual change between age 3 and age 18 in total behavior problems. Two types of growth functions (i.e., linear and quadratic) were fit to the data and assessed as to the adequacy of their fit by examining deviance (goodness of fit) tests of the full model. The quadratic model was found to be the best fitting model ( $X^2=38.39$ ,  $p<.001$ ).

All three parameters were statistically significant. The age 10 status parameter indicates that at age 10 years children's total behavior problems score was 55.93 on average, within the normal range (i.e., below the clinical cutoff score of  $T=60$ ). The linear change parameter was .46 indicating that the total behavior problem score increased, on average, at a rate of .46 T score units each year over the range from age 3 to age 18. The quadratic change parameter was -.07. Negative quadratic terms indicate convex trajectories. Therefore, overall, total behavior problems increase and then decrease. In other words, the linear rate of increase slows over time until it becomes zero and then negative.

Characteristics of the child (type of disability, gender, and health) and characteristics of the family system (parent health and parenting confidence) were tested as predictors of the status and change parameters. Only gender and child health were significant predictors of change. Gender was a positive and significant predictor of the linear change term only ( $\beta=.23$ ,  $p<.05$ ). Thus, girls experienced significantly greater increases in behavior problems over time but did not differ from boys in the rate at which this increase slowed and turned negative. Child health was a negative and significant predictor of the status parameter ( $\beta= -.67$ ,  $p<.001$ ). Children in better health had lower behavior problem scores than children in poorer health at age 10 years. Child health was

also a positive and significant predictor of the quadratic change parameter ( $\beta=.005$ ,  $p<.05$ ) but not of the linear change parameter ( $\beta=.001$ ,  $p>.05$ ). Therefore, better child health predicts a faster rate of decline in behavior problems than poorer child health.

*Hypothesis 2. Changes in the perceived peer acceptance of those with disabilities from middle childhood through adolescence are correlated with changes in their social skills and predicted by the characteristics of the child (type of disability and severity of cognitive impairment) and characteristics of relational aspects of the family system (marital relationship, parental social support).*

Data on peer acceptance were available for three time points; age 10, age 15, and age 18. Therefore, only two types of growth functions were tested and assessed as to the adequacy of their fit by examining deviance (goodness of fit) tests of the full model. First, a linear model was tested and the linear change parameter was not found to be statistically significant ( $\beta= -.004$ ,  $p >.05$ ). This indicates that on average, there is no change in peer acceptance that is different from zero. The variance component associated with this parameter, however, was statistically significant (variance component=.01,  $X^2=94.45$ ,  $p <.05$ ), indicating that there is variability around this parameter that may be explainable by level 2 predictors.

The second model entered social skills as a time-varying covariate. Time varying covariates are variables that are measured over the same time points as, and correlated with, the outcome variable. By including a time-varying covariate in the model, the time varying influence of that variable on the outcome is controlled. By controlling for social skills at each time point, the influence of social skills on change in peer acceptance is partialled out to get a “purer” estimation of change in peer acceptance. This second model was found to be a better fit to the data using a deviance (goodness of fit) test of the full model ( $X^2=8.25$ ,  $p<.01$ ). Overall, the linear change parameter was still not significant ( $\beta=-.02$ ,  $p >.05$ ) but the variance component was significant (variance component=.01,  $X^2=95.64$ ,  $p<.05$ ).

Characteristics of the child (type of disability and severity of cognitive impairment) and characteristics of the relational aspects of the family system (marital relationship and parental social support) were tested as predictors of the status and change parameters. Although none of the variables was a significant predictor of change, type of disability and helpfulness of social support were significant predictors of the status parameter. Children with Down syndrome in comparison to those with motor impairment and developmental delay had significantly higher peer acceptance scores at age 10 years ( $\beta=.54$ ,  $p<.05$ ). Also, mothers reporting greater social support helpfulness had children with higher peer acceptance scores at age 10 years than mothers reporting lower social support helpfulness ( $\beta=.03$ ,  $p<.05$ ).

*Hypothesis 3. Controlling for negative life events, maternal and paternal child-related stress will increase from the infant/toddler years through the adolescent years. In addition, the rate of change will accelerate from age 10 through age 18. Child behavior problems will drive the increase in stress for both mothers and fathers while greater*

*parenting confidence will partially mediate this increase. Gender of the child will interact with parent gender; fathers of sons will have the steepest increases in child-related stress throughout adolescence.*

The level-1 analysis tested two growth functions measured from entry into early intervention to age 18 years for maternal and paternal child-related stress. Each growth function controlled for negative life events as a time varying covariate. The quadratic growth function was found to be a better fit to the data than the linear model using a deviance (goodness of fit) test of the full model ( $X^2=675.41$ ,  $p<.001$ ). Although none of the parameters for either mothers or fathers was statistically significant, the variance component for each parameter was significant indicating that they may be explainable by level-2 predictors. On average, the pattern of the stress trajectory for mothers and for fathers shows an increase followed by a decrease.

Two child characteristics (gender and child behavior problems) as well as parenting confidence were tested as level-2 predictors. Although gender was not a significant predictor for either mothers or fathers, both child behavior problems and parenting confidence were significant predictors but in different ways. For mothers, both child behavior problems and parenting confidence were significant predictors of the status parameter. Greater behavior problems predicted more maternal stress ( $\beta=.06$ ,  $p<.001$ ) while more parenting confidence predicted less maternal stress at age 10 years ( $\beta=-.05$ ,  $p<.001$ ). Child behavior problems but not parenting confidence, was a significant predictor of the change parameters. Mothers of children with greater behavior problems experienced both a significantly greater increase in child-related stress ( $\beta=.003$ ,  $p<.001$ ) and less of a downturn in stress ( $\beta=-.0003$ ,  $p<.01$ ) than mothers of children with fewer behavior problems.

For fathers, as for mothers, both child behavior problems and parenting confidence were significant predictors of the status parameter. Greater behavior problems predicted more paternal child-related stress ( $\beta=.04$ ,  $p<.001$ ) while more parenting confidence predicted less paternal stress at age 10 years ( $\beta=-.05$ ,  $p<.001$ ). In contrast to mothers, however, parenting confidence, rather than child behavior problems, was a significant predictor of change. Although parenting confidence was not a significant predictor of the linear change parameter ( $\beta=.001$ ,  $p>.05$ ), it was a positive and significant predictor of the quadratic change parameter ( $\beta=0005$ ,  $p<.01$ ). Therefore, fathers with greater parenting confidence experienced a greater downturn in paternal child-related stress than fathers with less parenting confidence.

*Hypothesis 4. Changes in maternal and paternal depression from middle childhood to late adolescence will be predicted by different dimensions of the overall family ecology, specifically the extent of challenging life experiences that families report (negative life events such as divorce, going into debt,, etc.), characteristics of the child with DD (social skills and peer acceptance), and the affective qualities within the family (marital quality and parenting confidence).*

With just three time points of data, a linear growth function was the only level one model tested. The age 10 status parameter was statistically significant for both mothers and fathers. The average depressive symptoms scores for both mothers ( $\beta=9.97$ ) and fathers ( $\beta=10.03$ ) were well under the clinical cut-off score of 16. Neither of the linear change parameters was statistically significant, however. On average, the mothers rate of change was negative ( $\beta=-.073$ ) while the fathers rate of change was positive ( $\beta=.001$ ). The variance around each of these linear change parameters was statistically significant, indicating that they may be explained by level-2 predictors.

The number of negative life events experienced by the mother and father, two characteristics of the child (social skills and peer acceptance) and two affective qualities within the family (marital quality and parenting confidence) were tested as level-2 predictors. Negative life events and dyadic cohesion were both statistically significant predictors of the status parameter for both mothers and fathers. A greater number of negative life events predicted a higher depression score for mothers ( $\beta=4.04$ ,  $p<.05$ ) and fathers ( $\beta=4.05$ ,  $p<.001$ ) while more dyadic cohesion predicted a lower depression score for mothers ( $\beta=-.77$ ,  $p<.01$ ) and for fathers ( $\beta=-.86$ ,  $p<.001$ ) at age 10.

Different measures predicted change in maternal versus paternal depression. For mothers, more dyadic cohesion predicted more of a decrease in depression ( $\beta=.05$ ,  $p<.05$ ). For fathers, more negative life events predicted a greater increase in depression ( $\beta=.44$ ,  $p<.05$ ).

*Hypothesis 5. Adolescents who have fewer behaviors problems and whose parents have higher levels of parenting confidence will display higher levels of autonomy at age 18; the relation between behavior problems and autonomy will be mediated by the parent-teen relationship and moderated by the adolescent's level of adaptive skills*

This hypothesis was tested using hierarchical linear regression with separate models for mothers and fathers. Since the three autonomy measures (two completed by the adolescent, one by the primary caregiver) were correlated, a composite measure of autonomy was calculated and used as a dependent variable in the equations. Preliminary analyses indicated no statistical differences in autonomy by types of disability (Down syndrome or other DD), gender or their interaction ( $F=1.62$ ,  $F=1.96$ , and  $F=.61$ , all  $p>.05$  for type of disability, gender and their interaction respectively).

Adaptive skills did not enter the final equation as a main effect or as a moderator of behavior problems in relation to autonomy. In the final model (mothers), the mother-teen relationship was a positive and significant predictor of adolescent autonomy ( $\beta = .250$ ,  $p<.05$ ;  $R^2 = 6.2\%$ ,  $p<.05$ ). Teen behavior problems also added significant prediction of variance in teen autonomy ( $\beta = -.49$ ,  $p<.001$ ;  $\Delta R^2 = 20.3\%$ ,  $p<.001$ ). A statistical test of the mediational model indicated that teen behavior problems was a significant mediator of the relation between mother-teen relationship and teen autonomy (Sobel test=3.077,  $p=.002$ ). The positive relation between higher quality mother-teen relationship and more teen autonomy decreases when teen behavior problems are high.

The same analysis was run for fathers. Teen-father relationship was not a significant predictor of teen autonomy. The only significant predictor in the final model was teen behavior problems ( $\beta = -.501$ ,  $p < .01$ ,  $R^2 = 17.6\%$ ,  $p < .01$ ). Adolescents who had higher levels of behavior problems had lower levels of autonomy.

*Hypothesis 6. Maternal and paternal well-being when their adolescent with DD is age 18 will be predicted by the behavior problems displayed by their adolescent and family climate (i.e. teen-parent relationship and social support). In addition, maternal but not paternal well being will be influenced by an interaction between parenting tasks and adolescent autonomy. Mothers who are highly involved in parenting tasks but whose adolescent son or daughter displays a high level of autonomy will report lower levels of well being. In contrast, mothers who have high involvement in parenting tasks but whose adolescent son or daughter displays a low level of autonomy will report higher levels of well being.*

Analyses of models for mothers and fathers were conducted separately. For both parental higher well-being was operationalized as reporting lower levels of depressive symptomatology and more positive physical health. A composite measure of well-being was calculated separately for mothers and fathers. Preliminary analyses indicated no significant differences for mothers' well-being or fathers' well-being by teen type of disability, gender or their interaction ( $F=1.80$ ,  $F=1.26$ ,  $F=.003$  for mothers and  $F=2.90$ ,  $F=.001$ , and  $F=1.164$  for fathers for type of disability, gender and their interaction respectively, all  $p > .05$ ).

In the final model, for maternal well-being, teen behavior problems added 23.5% of the variance ( $F=31.56$ ,  $p < .001$ ,  $\beta = -.484$ ,  $p < .001$ ), and the family climate predicted an additional 9.0% of the variance ( $F=6.73$ ,  $p < .01$ ;  $\beta = -.045$ ,  $p > .05$ , NS for parent-child relationship and  $\beta = -.4-8$ ,  $p < .001$  for caregiving burden). Maternal social support added a significant 10.7% of the variance ( $F=18.85$ ,  $p < .001$ ;  $\beta = .360$ ,  $p < .001$ ). A combined 43.2% of the variance in maternal well-being was explained by the variables in the equation. The main effects of autonomy and the interaction between autonomy and parenting tasks were not significant. A Sobel test of mediation indicated that maternal social support was a significant mediator of the relation between caregiving burden and maternal well-being (Sobel =  $-3.5018$ ,  $p = .0005$ ). Thus, the relation between greater caregiving burden and less maternal well-being decreases when maternal social support is high,

Identical analyses were run for paternal well-being. In the final model, teen behavior problems added 6.0% of the variance ( $F=4.48$ ,  $p < .05$ ,  $\beta = -.245$ ,  $p < .05$ ), the family climate contributed an additional but non significant 7.8% of the variance ( $F=3.09$ ,  $p = .052$ , NS,  $\beta$  for father-teen relationship =  $.224$ ,  $p > .05$ , NS and father caregiving burden  $\beta = -.157$ ,  $p > .05$ , NS). Fathers' social support added a significant 9.8% of the variance ( $F=9.8$ ,  $p < .01$ ,  $\beta = .345$ ,  $p < .01$ ). The variables in the final equation predicted 18.2% of the variance in father well-being. The main effects of teen autonomy and the interaction between autonomy and parenting tasks were not significant.

In summary, for both mothers and father, teen behavior problems related negatively to well-being. The caregiving burden was an additional predictor for mothers (but not fathers). Social support, however, added significant prediction in a positive direction for the well-being of both mothers and fathers. For mothers, social support served as a mediator of the relation between caregiving burden and maternal well-being.

## **V. Discussion and Interpretation of Findings**

### **A. Conclusions**

Although many conclusions can be drawn from analyses conducted on this phase of this longitudinal study, a central issue is prominent: the importance of addressing behavior problems of children and adolescents with DD, even when the behavior problems may not be extreme. Behavior problems increased over time for girls and for both boys and girls who were not in excellent health. Adolescents with higher levels of behavior problems also exhibited lower levels of autonomy. Low levels of autonomy are of concern because they are likely to affect opportunities for employment and independent living. Finally, behavior problems predicted an increase in (and less of a downturn in) stress levels of mothers. At age 18, teen behavior problems related to more deleterious levels of well-being of both mothers and fathers.

### **B. Limitations**

This study is limited by its composition of participants, who are primarily Euro-American and of at least moderate income and education. Also, the study was conducted in the Northeast of the United States and may not generalize to other parts of the country. The sample does not include individuals with all types of disabilities, only those who were identified as having Down syndrome, motor impairment or developmental delay of unknown etiology during the infant or toddler years and whose families chose to enroll in early intervention.

In relation to measures, the study is limited by the use of many self-report measures. Independent observations were not used during this phase of the study, although cognitive performance of the adolescent was assessed using a standard instrument.

### **C. Comparison with findings of other studies**

Although this study is unique among studies of individuals with disabilities and their families because of its multi-year longitudinal design, the findings both build on and add important features to the current knowledge base. In relation to behavior problems, we found that the trajectory over time is not linear but quadratic. Other studies indicated that a higher level of behavior problems occur for those with DD during the adolescent period (Borthwick-Duffy, 1992; Richardson, Koller, & Katz, 1985) and although we found an increase in behavior problems we also found that the increase slowed over time and eventually demonstrated a decrease. These findings suggest that the middle childhood and early adolescent period may be a critical time for intervention regarding children's behavior problems.

The findings of this study also call into question the assumption of linear increases in parenting stress over the entire childhood and adolescent period (Wikler, 1986). The role of children's behavior problems in predicting changes in maternal stress is consistent with cross-sectional studies indicating that parenting stress often correlates with child behavior problems (Floyd & Gallagher, 1997). This study, however, provides evidence of increases in stress related to such behavior problems. The role of fathers' parenting efficacy has seldom been studied in relation to parenting a child with a disability. The finding that such efficacy predicted a downturn in parenting stress for fathers is consistent with prior literature indicating that greater parenting efficacy is associated with an increase in satisfaction with parenting (Johnston & Mash, 1989), and suggests that further consideration be given to the importance of parenting efficacy for fathers.

In relation to the mental health of parents, we found that depressive symptoms did not increase over time for the sample as a whole but that increases were found for subgroups based on the marital relationship and external events affecting the family but not directly related to the child with disabilities. These findings underscore the importance of moving away from the model that purports that parents have "chronic sorrow" due to their child with a disability (Kratochvil & Devereau, 1988). Instead, these findings suggest that although parenting a child with a disability is can be a challenge, such a responsibility does not necessarily impose long-term deleterious mental health on parents.

The peer acceptance of the participants with DD in this study also did not change over time. Building on studies that suggest a "Down syndrome advantage" (Hodapp, Ly, Fidler, & Ricci, 2001), we found that children with Down syndrome reported having greater acceptance from their peers at age 10. We also found that when mothers had stronger social support networks children's peer acceptance was greater. The importance of social support has been underscored in many studies (Dunst, Trivette, & Jodry, 1997; Hauser-Cram & Howell, 2003), and the findings of this study indicate that mothers' social support networks not only relate to their own well-being but may also have implications for their adolescent with DD. We speculate that acceptance of the adolescent may come through the mothers' social network and/or may be a result of modeling of friendship support by mothers and their friends.

#### **D. Possible application to MCH health care delivery.**

The findings from this study have important implications for MCH health care. This is the first study that has analyzed the relation between the physical health and behavior problems of youth with disabilities. The findings underscore the importance of addressing both of these issues when working with families of adolescents with DD. It suggests that pediatricians and other primary care physicians inquire about an adolescent's behavior problems and learn about resources to assist parents in helping to diminish and cope with their child's behavior problems.

#### **E. Policy implications**

A major policy implication from this study derives from the findings related to behavior problems of individuals with DD. As noted previously, this domain of development requires earlier and more effective interventions. Protocols are needed to

help health care providers determine in interaction with parents and the individual with DD the extent of behavior problems and how these problems may relate to physical health. These findings have implications for the training of health care providers as well as for the services available to families.

#### **F. Suggestions for future research**

This study has several implications for future research. First, in relation to behavior problems of youth with DD, it is imperative that research focus on identifying effective interventions. Such interventions need to be directed at helping the individual with DD learn techniques of self-control as well as at parents and service providers who can assist with the development of such techniques. If adequate, such interventions will not only result in declines in behavior problems and thus potentially more opportunities for employment and independent living but will also result in decreases in parenting stress.

The different models for mothers and fathers resulting from analyses of this data set suggest that more studies need to include fathers. Fathers bring a unique and important perspective to their parenting, and their role in parenting a child with a disability is often neglected in research (Hauser-Cram & Howell, 2003). Therefore, future research on the critical aspects of adaptation and well-being of fathers of adolescents with disabilities would generate important information to those who provide services to families.

#### **G. References**

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Table 1. Key Study Variables and Measures for Longitudinal Analyses:  
Hypotheses 1-4

<b>Construct</b>	<b>Measure</b>	<b>Psychometric Properties</b>	<b>Data Collection Method/Levels of Measurement</b>
<b><i>PREDICTORS:</i></b> <i>Measured at age 10</i>			
Child type of disability	Medical records	N/A	Review of records/ N
Child cognitive skills	Stanford-Binet Intelligence Scale (Thorndike et al., 1986)	Alphas = .80-.97	Assessment/ I
Child gender	EICS info. Form	N/A	Parent report(M)/N
Child health	Rand Health Survey (Eisen et al., 1980)	N/A	Parent questionnaire(M)/I
Child behavior regulation	Child Behavior Checklist (Achenbach & Edelbrock, 1983)	EICS alphas= .88-.89	Parent (M)/ questionnaire/I
Child-peer acceptance	Self-perception profile (Harter, 1985)	Alphas= .75-.80	Questionnaire/ Adolescent/ I
Child social skills	Vineland Adaptive Behavior Scales: Survey Form (Sparrow et al., 1989)	EICS alphas=.89-.97	Questionnaire-interview/ Parent (M)/ I
M/F Education/ Income	EICS Info. Form	N/A	Questionnaire (M/F)/I
M/F Health	EICS Info. Form	N/A	Questionnaire (M/F)/I
Parenting confidence	Family Experiences Questionnaire (Frank et al., 1986)	EICS alphas=.90-.91	Questionnaire(M/F)/I
Marital Quality	Dyadic Adjustment Scale (Spanier, 1976)	EICS alphas=.93-.94	Questionnaire (M/F)/I

Note. (1) I=Interval, N=Nominal level of measurement  
(2) M=Mother report, F=Father report

Table 2. Key Study Variables and Measures for Cross-sectional Analyses at Age 18: Hypotheses 5-6

<b>Construct</b>	<b>Measures</b>	<b>Psychometric properties</b>	<b>Data Collection Method/Level of Measurement</b>
<i>Predictor variables</i>			
Adol. Adaptive skills	Vineland Adaptive Behavior Scales: Survey Form (Sparrow, et al., 1989)	EICS alphas =.93 to .96	Parent (M) report/I
Adol. Behavior regulation	Child Behavior Checklist (Achenbach & Edelbrock, 1983)	EICS alphas .88-.89	Parent (M/F)/ questionnaire/I
Teen-parent relationship	Positive Affect Scale (Bengston, 1973)	Alpha=.88 to .91	Questionnaire, parent report (M/F)/I
Parenting confidence	Family Experiences Questionnaire (Frank, et al., 1986)	EICS alphas=.90-91	Questionnaire, parent report (M/F)/I
Parent social support	Social Support (Brandt & Weinert, 1981)	N/A	Parent interview (M/F)
Child social networking	Social Support of teen (EICS rev.) (Antonucci, 1986)	N/A	Parent interview (M/F)
Caretaking	Burden of Care Scale (Zarit, et al., 1980)	EICS alphas=.84 to .86	Questionnaire/, Parent report (M/F)/I
<i>Outcomes</i>			
Adol. autonomy	E-Z Personality Questionnaire (Zigler, et al., 2002)	Effectance motivation subscale alpha=.91	Questionnaire/parent (M/F)/I
	Decision-making Scale( Steinberg , 1987; rev by Holmbeck & O'Donnell, 1991)	Alphas=.75-.83	Questionnaire/ Parent report (M/F) adolescent report/I
	Quality of Life Questionnaire (Schalock & Keith, 1993)	Independence subscale alpha=.82	Questionnaire/ adolescent report/I
Parent psychological distress/depression	CES-D (Radloff, 1977)	EICS alphas=.90-.92	Questionnaire/parent report (M/F)/I
Parent physical health	SF-12 Health Survey (Ware et al., 1996)	Alpha=.76	Questionnaire/parent report (M/F)/I

Note. (1) Demographic variables for participants will be obtained from the EICS Age 18 information form, based on parent report (see Table 1)

(2) I=Interval level of measurement

N=Nominal level of measurement

(3) M=Mother report F-Father report

## VI. List of products

### THE EARLY INTERVENTION COLLABORATIVE STUDY

#### PUBLICATIONS: MONOGRAPHS

Hauser-Cram, P., Warfield, M.E., Shonkoff, J.P., & Krauss, M.W. with Sayer, A. & Upshur, C.C. (2001). Children with disabilities: A longitudinal study of child development and parent well-being. *Monographs of the Society for Research in Child Development*, 66 (3, Serial No. 266).

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#### PUBLICATIONS: ARTICLES (\* produced during this project period)

Mitchell, D.B., & Hauser-Cram, P. (in press). The well-being of mothers of adolescents with developmental disabilities in relation to medical care utilization and satisfaction with health care. *Research in Developmental Disabilities*.\*

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**PUBLICATIONS: BOOK CHAPTERS** (\* produced during this project period)

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Hauser-Cram, P., & Gridley, M. (2003). Early childhood education. In J. Miller, R. Lerner, L.R. Schiamberg, & P. Anderson (Eds.), *Encyclopedia of human ecology*, Denver: ABC-CLIO.\*

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### **PRESENTATIONS (during this project period)**

Hauser-Cram, P. (2007). *Early education and early intervention*. Paper presented at the NIPPA Early Years Organization, Belfast, N. Ireland, March 8,

Hauser-Cram, P. (2007). *Longitudinal research on children with developmental disabilities and their families*. Paper presented at St. Patrick's College, Drumcondra, Dublin, Ireland., March 12.

Hauser-Cram, P. (2007). *Young children with developmental disabilities*. Paper presented at the Dublin Institute of Technology, Dublin, Ireland, March 13.

Hauser-Cram, P. (2007). *Education across generations: Lessons learned from investigating pathways*. Paper presented at the Society for Research in Child Development, March 31. Boston.

Mitchell, D.B., Hauser-Cram, P., Kersh, J., & Warfield, M.E. (2007). *Family processes and parent relationships with adolescents with developmental disabilities*. Paper presented at the Society for Research in Child Development, March 30. Boston.

Kersh, J., Hauser-Cram, P., & Pan, H. (2007). *Inclusive education and social isolation among adolescents with Down syndrome*. Paper presented at the Gatlinburg Conference on Theory and Research on Mental Retardation and Developmental Disabilities, Baltimore, March.

Warfield, M.E. (2007). *Early intervention collaborative study (EICS): An overview*. Paper presented at the Section on Pediatrics, APTA, Research Summit II Conference entitled "Early intervention for with or at risk for disabilities, Alexandria, VA, October.

Hauser-Cram, P., & Mitchell, D.B. (2006). *From early intervention to mid-adolescence: The well-being of teens with developmental disabilities*. Paper presented at the Maternal and Child Health Symposium, Harvard School of Public Health, Boston, December 1.

Mitchell, D.B., & Hauser-Cram, P. (2006). *Maternal relationships with adolescents with intellectual disabilities*. Paper presented at the PTRMR Conference, Liege, Belgium, June.

Hedvat, T.T., Hauser-Cram, P., & Warfield, M. E. (2005). *The contribution of marital satisfaction to the well-being of parents of children with developmental disabilities*. Poster presented at the Society for Research in Child Development, Atlanta, April 7.

Howell, A.N., & Hauser-Cram, P. (2005). *Growth in mothers' interactions with infants who have Down syndrome*. Poster presented at the Society for Research in Child Development, Atlanta, April 7.

Warfield, M.E. (2005). *From protection to pro-action: Theory and research on families of children with disabilities*. Paper presented at the McGill University Conference entitled "Chronic Pediatric Illness: The Impact on Children and their Families, Montreal, April.

Warfield, M.E. (2005). *The relevance of relationships to development: Findings from a longitudinal study of children with disabilities*. Paper presented at the McGill University Conference entitled "Chronic Pediatric Illness: The Impact on Children and their Families, Montreal, April.

Young, J.M., Howell, A.N., & Hauser-Cram, P. (2005). *Predictors of mastery motivation in children with disabilities born preterm*. Poster presented at the Society for Research in Child Development, Atlanta, April 9.

Hauser-Cram, P. (2004). *A longitudinal study of children with developmental disabilities*. Invited presentation to the Newborn Epidemiology Clinic Research Seminar, Beth Israel Hospital, Boston, MA, Nov. 4.

Hauser-Cram, P. (2004). *Lessons from the Early Intervention Collaborative Study*. Invited presentation to the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program, Shriver Center, Waltham, MA, Oct.21.

Hauser-Cram, P. (2004). *Early Intervention participants at age 3: Information inquiry and implications, reflections on the National Early Intervention Longitudinal Study*. Presented at Head Start's 7<sup>th</sup> Annual National Research Conference, Washington, DC., June 29.

Hauser-Cram, P., & Kersh, J. (2003). *Often overlooked parents: Fathers of children with developmental disabilities*. The Academy of the American Association on Mental Retardation, Chicago, May 23.

Kersh, J., & Hauser-Cram, P. (2003). *Predictors of well-being in fathers of children with disabilities*. Poster presented at the Society for Research in Child Development, Tampa, April 26.

Hauser-Cram, P. (2002). *Sometimes I wish I didn't have this Down syndrome: Insights and evidence from a longitudinal study*. Invited address, Denison University, Granville, OH, Oct. 4.