

## The Early Intervention Collaborative Study: Young Adulthood (R40MC08956): Final Report

### I. Introduction

- A. Nature of the research problem.** This three-year investigation was a continuation of the Early Intervention Collaborative Study (EICS), a longitudinal investigation of children and families who participated in Early Intervention services because of a child's early special needs (Down syndrome, motor impairment, or developmental delay of unknown etiology) identified before 24 months of age. This study was undertaken to determine the developmental trajectories of individuals with disabilities and of parents' adaptation from early childhood to young adulthood (YA). The young adult period is of particular interest because of the many transitions required at this life phase. This study focused on MCHB Strategic Research Issue IV in relation to conducting longitudinal studies of special populations as well as on Issue I in relation to health care transitions of children with special needs. In general, this investigation focused on Healthy People 2010 goals of producing findings to improve the health and well-being of people with disabilities.
- B. Purpose, scope, and methods of investigation.** This phase of the study focused on these individuals at age 23 as they "aged out" of special education services. This phase had two general aims: (1) to determine practice and/or policy-relevant predictors of advantageous and deleterious patterns of trajectories of individuals with DD and their parents as they progressed from early childhood to young adulthood; and (2) to determine the satisfaction with post-school transitions and whether such transitions enhance (or disrupt) the change in these trajectories. We investigated these through participant interviews and responses to questionnaires. Statistical procedures involved group-based trajectory modeling (PROC TRAJ; Jones, Nagin, & Roeder, 2001) along with multiple regression and logistic regression statistical procedures.
- C. Nature of the findings.** Analyses of trajectories analyzed from early childhood to young adulthood, indicated (as predicted) distinct trajectories of child behavior problems (both internalizing and externalizing), child social skills, and child daily living skills. Child behavior problem trajectories differed based on family processes with more advantageous trajectories for children in families reporting higher levels of cohesiveness and greater parental efficacy. Trajectories of parenting stress also followed distinct trajectories with the highest levels of parenting stress generally occurring during the middle childhood period. Negative life events and child internalizing behavior problems related to more deleterious trajectories in parenting stress for both mothers and fathers. Mothers' use of problem-focused coping was related, to some extent, to more positive trajectories in parenting stress. Trajectories of children's daily living skills showed two patterns of decline (in standard scores) over time, with patterns differing based on children's cognitive performance scores. The trajectories in social skills showed three distinct groups with declines (in standard scores) for all three groups from early through middle childhood and an increase in one group during adolescence to young adulthood. The differences among the groups were accounted for by cognitive performance scores.

In relation to questions about transition, the majority of young adults (78%) had made the transition from pediatric to adult-oriented physicians. The young adults with higher skills in daily living were better prepared for making this transition as were young adults from families reporting lower levels of maternal parenting stress. Young adults with higher levels

of functional skills also were reported to have made a more successful transition from secondary school to other productive activities (postsecondary education, vocational services or daily activities programs). Also, young adults whose parents had met with school personnel prior to leaving secondary school made a more successful transition.

Nevertheless, almost half of the mothers (43%) reported having to make significant changes in their own daily lives due to the transition out of school. Finally, we found that few young adults (22 %) had made the transition from living in their parents' home to an independent living situation, although about one third (33% ) of mothers of young adults living at home reported expecting the young adult to live independently in the future.

## II. Review of the Literature

This study was designed by building on several complementary theoretical models: developmental systems models (Sameroff, 1995; Lerner, 1991), risk and resilience models (Luthar, Cicchetti, & Becker, 2000) and life course theory (Baltes, Reese, & Lipsitt, 1980). Together these theoretical models emphasize the value of longitudinal investigations in understanding predictors of advantageous and deleterious change, the importance of context to development, especially the proximal processes that occur within the family, and the differing societal and personal expectations during each life phase of both children and parents. In this phase of the study, we were also informed by the work of Arnett (2001), who proposed that the ages of 18-25 are a distinct life phase in which the YA is honing the development of skills (through school, work or a combination) for meaningful employment, is becoming increasingly financially self-sufficient, and has started making his or her own decisions about adult responsibilities. Additionally, according to the American Academy of Pediatrics (AAP) guidelines (AAP, 2002), the transition from pediatric or adolescent to adult health care service also occurs at this life phase (Reiss, Gibson, & Walker, 2005). In their book on the transition to adulthood of vulnerable populations, Osgood, Foster, Flanagan, and Ruth (2005) point out how little we know about this important life phase especially for those who "age out" of service systems. In particular, behavior problems often impede opportunities for those with developmental disabilities (Tonge, 1999) whereas positive functional skills are likely to enhance those opportunities (Wehmeyer & Garner, 2003). In addition, parents often need to serve as a source of support for the transitions of young adults; parenting stress is a factor that can impede adaptive functioning of parents and limit parental support yet may be amenable to change through service provision (Hastings & Beck, 2004).

## III. Study Design and Methods

- A. **Study design.** EICS is a non-experimental, longitudinal investigation. For ethical reasons, EICS was designed to be a study of within-group differences with no control group as all children with DD were eligible for early intervention services.
- B. **Population studied.** This investigation was restricted to families of children with early identified special needs (Down syndrome, motor impairment, or developmental delay of unknown etiology) who entered early intervention services in one of two states (Massachusetts, New Hampshire) before 24 months of age and agreed to participate in this study.
- C. **Sample selection.** EICS began in 1984 and this investigation has followed an initial group of 190 infants and toddlers with DD (n=54 Down syndrome, n=77 motor impairment, n=59 developmental delay of unknown etiology). Sample attrition was approximately 10% at each data collection point resulting in n=131 families at age 18. At age 23 a larger rate of

attrition occurred with approximately 61% retention rate. A total of n=243 individuals chose to participate, including 77 caregivers (primarily mothers), 48 co-caregivers (primarily fathers), 74 young adults, and 44 siblings. In general, parents in these families were highly educated (51.2 % of mothers had a college degree whereas 25% had a high school degree or less) and identified as white (96 %); 76% of mothers were married at the age 23 data collection point.

**D. Instruments used.** The following instruments were used to assess functioning in the young adults: Assessment of behavior problems. We measured behavior problems using Child Behavior Checklist (CBCL) (ages 2-3, ages 4-18) (Achenbach, 1991; Achenbach & Edelbrock, 1983; Achenbach & Rescorla, 2003) at ages 3, 5, 10, 15, 18, 23. Assessment of functional skills (social skills and daily living skills) was examined using the Vineland Scales of Adaptive Behavior (VABS, Sparrow, Balla, & Cicchetti, 1984; Vineland-II, Sparrow, Cicchetti, & Balla, 2005) at ages 1, 2, 3, 5, 10, 15, 18 and 23. We used standard measures of cognitive performance throughout this study including the Bayley Scales (Bayley, 1969) during the infant/ toddler years, the McCarthy Scales of Children's Abilities (McCarthy, 1972) during preschool and the Stanford-Binet (Thorndike et al., 1986, Roid, 2003) during middle childhood, adolescence, and at age 23. Loneliness was based on the Loneliness Scale (Williams & Asher, 1992). Autonomy was based on the E-Z Personality Questionnaire (Zigler et al., 2002). Mastery Motivation was operationalized as persistence on a problem-posing task (Morgan et al, 1991). The child health report (medical record) indicated the presence or absence of a seizure disorder. The quality of the sibling relationship was based on the Sibling Relationship Questionnaire (Buhrmester & Furman, 1990). Alphas on all questionnaires were in the acceptable to good range.

The following instruments were used to measure family processes: Family cohesion was measured by the cohesion subscale of the FACES IV (Gorall, Tiesel & Olson, 2006). Aspects of parent well-being were assessed using the Parenting Stress Index (Abidin, 1995) to capture dimensions of stress emanating from characteristics of the child (e.g., distractibility) and the demands of the parenting experience (e.g., social isolation) at each data point from the study's inception. At age 23 we used the adolescent version of this instrument (Sheras, Abidin, & Konold, 1998). Negative life events were measured using the Life Events Scale (Abidin, 1995), which is a list of positive and negative events, (e.g., divorce, marriage, death of a family member, loss of job, increase in income). YA-parent relationship was measured by the Positive Affect Scale (Bengtson & Schrader, 1990) which indicates the extent of positive feelings between the young adult and a parent. Parenting efficacy was measured by the parenting confidence subscale of the Family Experiences Questionnaire (FEQ) (Frank et al., 1986). Parent coping was measured using the Ways of Coping Checklist (Folkman & Lazarus, 1980). Social support was based on the Personal Resources Questionnaire (Brandt & Weinert, 1981). Alphas on all questionnaires were in the acceptable to good range.

To assess the transition process we used sections of the Parent Involvement in Transition Planning Questionnaire (PITPQ), the Transition Experiences Survey (Kraemer & Blacher, 2001), and questions on health transition issues included in the SLAITS National Survey of Children with Special Health Care Needs (CDC, 2005).

**E. Statistical techniques employed.** Analyses of trajectories were conducted using group-based trajectory modeling (PROC TRAJ) (Nagin, 1999, 2005) which allows the identification of the number and shape of unique latent trajectories in the data as well as proportion of participants in each group. Other analyses involved logistical regression and multiple OLS regression. (See detailed description in next section.)

IV. **Detailed Findings.** A series of seven hypotheses were tested in this phase of EICS. The specific hypotheses and results are presented below. The first four hypotheses focused on longitudinal trajectories. To examine these we employed a two-step analytic method. The first step was to identify participants' trajectory group membership. This was achieved using group-based trajectory modeling (PROC TRAJ; Jones, Nagin, & Roeder, 2001; Nagin, 1999, 2005). This analytic technique enabled us to identify the number of unique latent trajectories in the data, the shape of those trajectories (i.e., flat, linear, quadratic, cubic, or quartic), as well as the proportion of participants belonging to each of the latent trajectory groups for each of our outcomes of interest. For this component of the analyses only unconditional models were fit to the data. Final models were based on examination of the Bayesian Information criterion (BIC) model fit statistics (Nagin, 2005). As an additional measure of model fit, the average posterior probabilities of individuals assigned to each group are reported. A minimum average posterior probability of .70 supports acceptable model fit (Nagin, 2005). Upon determining the best-fitting models for each of our longitudinal outcomes, each participant's predicted latent trajectory group membership was outputted as a variable to be used in the second step of our two-step analytic process, the goal of which was to determine what factors were associated with latent trajectory group membership. This goal was achieved using multinomial logistic regression. Latent trajectory group memberships were estimated using full information maximum likelihood (FIML) (Jones et al., 2001). Therefore, latent trajectory group membership on each of our longitudinal outcomes could be estimated for each participant regardless of whether or not there were missing data. Nonetheless, participants for whom there were less than two data points were excluded from our analyses, given the potential instability of growth estimates based on fewer than three data points (Rogosa, Brandt & Zimowski, 1982). In order to retain as much of our sample as possible in the logistic regression analyses, we replaced missing values using multiple imputation (Schafer, 2001). Following recommendations from Schafer, we imputed five data sets and pooled them in order to get reasonable parameter estimates.

**Hypothesis 1: (a). Distinct groups of trajectories will be found by analyzing child behavior problems from early childhood (age 3) through young adulthood (age 23). A high chronic trajectory, a low stable trajectory, and an increasing trajectory are expected. (b). Child and family characteristics measured in early childhood, middle childhood, and adolescence will discriminate these three trajectory groups. Specifically, we propose that membership in each trajectory group will vary by type of disability; presence of seizure disorder in early childhood; family cohesion during early and middle childhood; and parental efficacy in adolescence.**

- (a) Four internalizing behavior problems trajectories were identified (N=166): 1) Low Declining (14%), 2) Moderate Declining (43%), 3) Moderate Increasing (30%), and 4) High Peaking in Adolescence (11%). As seen in Figure 1, children in the Low Declining group had consistently low internalizing behaviors across time points. Internalizing

behaviors started for this group at a t-score of 45 in early childhood and decreased linearly to a t-score of 35 in young adulthood. Children in the Moderate Declining group started with a t-score of approximately 55 in early childhood, which decreased to 50 by middle childhood and remained stable through young adulthood. This group's trajectory was defined by a quartic function. Children in the third group, Moderate Increasing, started with internalizing behaviors similar to those in the Moderate Declining group. Internalizing behaviors increased from early childhood through adolescence for this group, however, peaking at a t-score of approximately 60. From mid-adolescence to young adulthood, internalizing behaviors decreased slightly to a t-score of 55. This group's trajectory was defined by a quadratic function. The final group consisted of children with high initial internalizing behaviors (t-score of approximately 65) that increased through adolescence, peaking at a t-score of approximately 70. From adolescence through young adulthood, internalizing behaviors decreased to approximately 65. This group's trajectory was defined by a quadratic function.

Three externalizing behavior problems trajectories were identified (N=166): 1) Low Increasing (22%), 2) Moderate Stable (33%), and 3) High Peaking in Middle Childhood (24%). As seen in Figure 2, children in the first group had low levels of externalizing behaviors from early childhood through adolescence, with a t-score of approximately 35-40. Externalizing behaviors increased from mid-adolescence through young adulthood for this group, ending at a t-score slightly above 40. This group's trajectory was defined by a quadratic function. Children in the Moderate Stable group had t-scores between 45 and 50 from early childhood through young adulthood. This group's trajectory was defined by a linear function, since externalizing behaviors increased gradually across time points. The final group of children started with high externalizing behaviors in early childhood (at approximately 55), which increased through middle childhood, peaking at approximately 65. Externalizing behaviors subsequently decreased in this group, ending at approximately 55 by young adulthood. The High Peaking in Middle Childhood group's trajectory was defined by a quadratic function.

It was expected that child behavior problems would fall into three distinct trajectories: a high chronic trajectory, a stable low trajectory, and an increasing trajectory. A high chronic trajectory was found for both internalizing and externalizing behaviors, although behavior problems peaked slightly in middle childhood or adolescence for these groups. A stable low trajectory was found for both internalizing and externalizing behaviors. In the case of internalizing behaviors, symptoms decreased slightly over time within the lowest group. For externalizing behaviors, symptoms were found to increase slightly over time for the lowest group. An increasing trajectory was also expected for child behavior problems. Although a dramatic increase from early childhood through young adulthood was not found, a group of children were found to increase slightly in internalizing symptoms over time. Similarly, there was a group of children whose externalizing behaviors increased slightly over time. Overall, the hypothesized trajectories were partially supported, although additional patterns were also found.

- (b) The likelihood of children falling into each of the internalizing behavior trajectory groups based on type of disability, presence of seizure disorder, family cohesion, and parenting

efficacy was compared to the likelihood of falling into the Low Declining trajectory group. Children with a diagnosis of Down syndrome were more likely (trend level) to follow the Moderate Increasing or High Peaking in Adolescence trajectories. A diagnosis of motor impairment significantly increased the likelihood of children following the Moderate Increasing trajectory. Higher parental perceptions of parenting efficacy during adolescence decreased the likelihood of children following the Moderate Increasing and High Peaking in Adolescence trajectories. Presence of a seizure disorder and parents' perceptions of family cohesion during early childhood were unrelated to children's internalizing behaviors trajectory group membership.

The likelihood of children falling into each of the externalizing behavior trajectory groups based on type of disability, presence of seizure disorder, family cohesion, and parenting efficacy was compared to the likelihood of falling into the Low Increasing trajectory group. More positive parental perceptions of family cohesion during early childhood and higher parental perceptions of parenting efficacy during adolescence decreased the likelihood of children following the High Peaking in Middle Childhood trajectory of externalizing behaviors. Type of disability and presence of a seizure disorder were unrelated to children's externalizing behaviors trajectory group membership.

It was expected that child and family characteristics measured in early childhood, middle childhood and adolescence would discriminate child behavior problems trajectory groups. Consistent with hypothesis 1b, type of disability related to internalizing behavior trajectories. Type of disability was not related to externalizing behavior trajectories, however. Presence of a seizure disorder during early childhood was expected to impact trajectory group membership, however this was not found. As expected, parents' perceptions of family cohesion during early childhood and parenting efficacy during adolescence impacted children's behavior problems trajectories. Family cohesion was uniquely related to externalizing behaviors whereas parenting efficacy related to both internalizing and externalizing behaviors.

**Hypothesis 2. (a) Distinct groups of trajectories will be found by analyzing social skills from infancy/toddlerhood through young adulthood (age 23). A low stable trajectory, a steady increase trajectory, and a child increase with adolescent stable trajectory are anticipated. (b). Child and family characteristics measured in early childhood, middle childhood, and adolescence will discriminate groups of children characterized by the three hypothesized trajectories. Specifically, we expect membership in the trajectory groups to relate to children's cognitive skills over time. After controlling for cognitive skills over the life span, mother-child interaction in early childhood, the parents' satisfaction with social support during middle childhood, and both the sibling relationship and the parent-teen relationship during adolescence will predict membership in the trajectory groups.**

- (a) In this model, participants' standardized scores on the Social Skills sub-domain of the Vineland were used as the outcome measure (N=195). There were 3 distinct latent trajectories identified in the data. The first group (Low; 24.0% of the sample) was characterized by a quartic growth function, showing a sharp decline from infancy to early childhood, followed by a moderate decline from early childhood to adolescence. Finally,

social skills increase slightly from late adolescence to young adulthood for this group. The scores for this group were consistently lower than the other two groups. The second group (Moderate; 46.5% of the sample) also followed a quartic function. Similar to the first group, social skills sharply declined from infancy through early childhood, moderately declined from early childhood to adolescence, and increased from late adolescence to young adulthood. The third group (High; 29.5% of the sample) was characterized by a cubic growth function, with a sharp decrease during early childhood, followed by a more gradual decrease through age 15 and finally a slow increase between age 15 and age 23. Overall the High group showed consistently greater functioning in this domain than the Moderate group (see Figure 3).

- (b) In these analyses, we examined what hypothesized factors predicted likely membership into the trajectory groups described above. Average participant cognitive performance was included as a control variable in this analysis, while mother-child interaction in early childhood, maternal satisfaction with social support during middle childhood, sibling relationship, and parent-teen relationship during adolescence were included as test predictors. The Low group was used as the reference group for this analysis. Of all of the predictors included, only average participant cognitive performance was significantly associated with a change in likelihood of group membership. For both Moderate and High groups, the coefficient was positive. Thus, for every one-unit increase in average cognitive performance, the odds of being in Moderate group relative to the Low group and the odds of being in High group relative to the Low group increase, holding all other predictors in the model constant.

**Hypothesis 3. (a). Distinct trajectories of daily living skills will be found in analyses from infancy/toddlerhood through young adulthood (age 23). A low stable, a slow increasing, and a rapid increasing trajectory are hypothesized for YAs. (b). We hypothesize that specific characteristics of children and families will predict these different trajectories. Controlling for cognitive skills, we expect that children's mastery motivation during early childhood and their autonomy during adolescence as well as parents' sense of efficacy during middle childhood will predict different trajectories.**

- (a) In this model, participants' standardized scores on the Daily Living Skills sub-domain of the Vineland were used as the outcome measure (N=195). As seen in Figure 4, two distinct latent trajectories were identified in the data. The first group (High; 51.2% of the sample) was characterized by a cubic growth trajectory, displaying rapidly declining scores during early childhood, followed by a plateau through age 15. Between the ages of 15 and 18, there was an increase in scores, followed by a slow decline between the ages of 18 and 23. The second group (Low; 48.8% of the sample) was characterized by a quartic growth trajectory with scores decreasing sharply during early childhood and then more gradually through age 15. Between the ages of 15 and 18 there was an increase in scores, which continued into early adulthood, though more gradually. This group's scores were consistently lower than the scores for the High group.
- (b) In these analyses, we examined what factors predicted likely membership into the trajectory groups described above. Average participant cognitive performance was included as a control variable in this analysis while children's performance on the puzzle task and the means' end task (separate indicators of mastery motivation), autonomy during adolescence and maternal sense of efficacy during middle childhood were included as test predictors. Because there were only two groups identified in the data,

binary logistic regression was used, with the High group as the reference group. Only average participant cognitive performance was significantly associated with a change in likelihood of group membership. Again, this coefficient was positive. Thus, for every one-unit increase in average cognitive performance, the odds of being in Group 1 relative to Group 2 increase, holding all other predictors in the model constant.

**Hypothesis 4. (a). Distinct groups of trajectories will be found by analyzing parenting stress from infancy/toddlerhood through young adulthood (age 23). A moderate increasing trajectory, an early increase and later decline trajectory, and a moderate stable trajectory are expected for both mothers and fathers. (b). Child and family characteristics measured in early childhood, middle childhood, and adolescence will discriminate groups of mothers and fathers characterized by the proposed trajectories. Specifically, we posit that a consistent pattern of negative life events over time will correlate with high levels of parenting stress over time. In addition, we expect that the parenting stress trajectory groups will differ based on type of disability, early childhood indicators of behavior problems, and children’s loneliness reported in middle childhood. Finally, parents’ use of problem-focused coping in adolescence will also relate to trajectories of parenting stress.**

(a) To test hypothesis 4a, unconditional models were fit for mothers (N=186) and fathers (N=182) separately to identify the number and shape of trajectory groups. *For mothers, four parent-domain stress trajectories were identified* (see Figure 5): 1) Stable Low (30%), 2) Moderate Steady Declining (10%), 3) Peak in Middle Childhood (35%) and 4) Stable High (24%). As seen in Figure 5, mothers in the Stable Low group had consistently low stress scores across time points. This group’s trajectory was defined by an intercept only model, with stress scores stable at approximately the 20th percentile. Mothers in the Moderate Steady Declining group started with high stress scores at approximately the 80th percentile, which decreased linearly to approximately the 15th percentile by young adulthood. The third group, Peak in Middle Childhood, started with moderate stress scores in infancy at approximately the 40th percentile, which increased until middle childhood at approximately the 65th percentile then subsequently decreased from middle childhood through young adulthood, returning to approximately the 40th percentile. This group’s trajectory was defined by a quartic function. Mothers in the final group, Stable High, had consistently high stress scores over time. This group’s trajectory was defined by a cubic function, with scores starting at approximately the 70th percentile, peaking slightly in middle childhood near the 90th percentile, and subsequently decreasing and returning to approximately the 70th percentile in young adulthood.

A similar pattern was found for *fathers’ parent-domain stress*, with 30% in the Stable Low group, 33% in the Peak in Middle Childhood group, 10% in the Moderate Declining group and 27% in the Stable High group (see Figure 6). Similar to mothers, fathers in the Stable Low group had consistently low stress across time points at approximately the 20th percentile. Fathers in the Moderate Declining group started with high stress scores at approximately the 65th percentile, which decreased linearly to approximately the 15th percentile by young adulthood. Fathers in the Peak in Middle Childhood group started with low stress scores in infancy at approximately the 30th percentile, which increased until middle childhood at approximately the 65th percentile then subsequently decreased slightly from middle childhood through young adulthood, ending at approximately the 60th percentile. This group was defined by a quartic function. Unlike mothers, fathers in the Peak in Middle Childhood group did not return to the same level of stress in

infancy. Instead, stress in young adulthood was higher than the stress they experienced in their child's infancy. Stress for fathers in the final group was defined by a cubic function. Fathers in the Stable High group had consistently high stress scores over time. Compared to mothers, fathers in this group experienced a more visible peak in stress during middle childhood, where scores were at approximately the 85th percentile. Stress scores started in infancy and ended in young adulthood near approximately the 65th percentile.

*For child-domain stress, three trajectories were identified for mothers* (see Figure 7): 1) Stable Low (22%), 2) Peak in Middle Childhood (37%) and 3) High Declining (40%). Mothers in the Stable Low group had stress scores that started near the 30th percentile in their child's infancy then gradually declined to the 25th percentile in young adulthood, following a linear function. Mothers in the Peak in Middle Childhood group had moderate stress scores near the 45th percentile in their child's infancy, which increased until middle childhood at approximately the 70th percentile then subsequently decreased from middle childhood through young adulthood, ending near the 35th percentile. This group's trajectory was defined by a quartic function. Mothers in the final group had stress scores that started high, near the 80th percentile, peaked slightly in early to middle childhood at the 90th percentile then subsequently declined to the 50th percentile in young adulthood, following a curvilinear pattern.

*Fathers' child-domain stress scores followed four trajectories* (see Figure 8): 1) Stable Low (19%), 2) Peak in Adolescence (25%), 3) High Declining (24%) and 4) Stable High (32%). Patterns for the first three groups were similar to mothers', but fathers' had an additional group with stable high child-domain stress scores. Fathers in the Stable Low group had stress scores that started near the 30th percentile in their child's infancy then gradually declined to the 10th percentile in young adulthood. Scores in this group were defined by a quadratic function. Fathers in the Peak in Adolescence group had moderate stress scores near the 40th percentile in their child's infancy, which increased until adolescence at approximately the 80th percentile then subsequently decreased from adolescence to young adulthood, returning to the 40th percentile. This group's trajectory was defined by a quadratic function. Fathers in the High Declining group had stress scores that started near the 80th percentile and declined over time, ending near the 25th percentile in young adulthood. This group's trajectory was defined by a quadratic function. The final group of fathers had stable child-domain stress scores. This group's trajectory was defined by an intercept only, since stress scores remained at approximately the 85th percentile across most time points.

It was expected that mothers and fathers would fall into three distinct parenting stress trajectories: a moderate increasing trajectory, an early increase and later decline trajectory, and a moderate stable trajectory. A moderate increasing trajectory was not found for parents' child- or parent-domain stress. For parents' child- and parent-domain stress, a trajectory of early increase and later decline was found. Although stress was expected to peak in early childhood, it was actually found to peak in middle to late childhood. A moderate stable trajectory was not found for parents' child- or parent-domain stress. Rather, stress was generally found to follow two distinct trajectories for child- and parent-domain stress, one of stable low stress and one of stable high stress.

(b) Conditional models were fit to examine the association between type of disability, behavior problems, and problem-focused coping with parents' trajectory group membership. Negative life

events were included as a time varying covariate in each model. Children's loneliness in middle childhood was not included as a predictor in the conditional models due to a limited number of children who were able to report on this measure. *For mothers' parent-domain stress trajectories*, negative life events was a statistically significant covariate for the Stable High group only ( $b = 1.93$ ,  $t(185) = 1.99$ ,  $p = 0.04$ ), with greater negative life events associated with greater parent-domain stress within this group. The likelihood of mothers falling into each of the trajectory groups based on type of disability, internalizing behavior, externalizing behavior, and problem-focused coping was compared to the likelihood of falling into the Stable Low trajectory group. Higher levels of internalizing behaviors increased the likelihood of mothers following the Moderate Declining and Stable High trajectories. Higher internalizing behaviors also increased the likelihood of mothers following the Peak in Middle Childhood trajectory (trend level). Lower use of problem-focused coping increased the likelihood of mothers following the Stable High trajectory significantly and the Peak in Middle Childhood trajectory (trend level). Type of disability and externalizing behaviors were unrelated to mothers' parent-domain stress trajectory group membership.

*For fathers' parent-domain stress trajectories*, negative life events was a statistically significant covariate for the Peak in Middle Childhood ( $b = 5.99$ ,  $t(181) = 2.15$ ,  $p = 0.03$ ) and Moderate Declining ( $b = 4.72$ ,  $t(181) = 3.11$ ,  $p < 0.01$ ) groups only. Greater negative life events were associated with greater parent-domain stress within these groups. The likelihood of fathers falling into each of the trajectory groups based on type of disability, internalizing behavior, externalizing behavior, and problem-focused coping was compared to the likelihood of falling into the Stable Low trajectory group. Fathers were more likely (trend level) to follow the Moderate Declining trajectory if their child had a diagnosis of motor impairment. The likelihood of fathers following the Moderate Declining and Stable High trajectories were increased if their child had higher levels of internalizing behaviors. Higher internalizing behaviors also increased the likelihood of following the Peak in Middle Childhood group (trend level). Externalizing behaviors and problem-focused coping were unrelated to fathers' parent-domain stress trajectory group membership.

*For mothers' child-domain stress trajectories*, negative life events was a statistically significant covariate for the Peak in Middle Childhood ( $b = 2.99$ ,  $t(185) = 1.28$ ,  $p = 0.02$ ) and High Declining ( $b = 2.30$ ,  $t(185) = 2.07$ ,  $p = 0.04$ ) groups only. Greater negative life events were associated with greater child-domain stress within these groups. The likelihood of mothers falling into each of the trajectory groups based on type of disability, internalizing behavior, externalizing behavior, and problem-focused coping was compared to the likelihood of falling into the Stable Low trajectory group. Having a child with higher levels of internalizing behaviors and externalizing behaviors increased the likelihood of mothers following the High Declining trajectory. Type of disability and problem-focused coping were unrelated to mothers' child-domain stress trajectory group membership.

*For fathers' child-domain stress trajectories*, negative life events was a statistically significant covariate for the Peak in Adolescence group only ( $b = 5.12$ ,  $t(181) = 3.28$ ,  $p < 0.01$ ), with greater negative life events associated with greater child-domain stress within this group. The likelihood of fathers falling into each of the trajectory groups based on type of disability, internalizing behavior, externalizing behavior, and problem-focused coping was compared to the

likelihood of falling into the Stable Low trajectory group. Having a child with higher internalizing behaviors increased the likelihood of fathers following the High Declining and Stable High trajectories. Higher externalizing behaviors increased the likelihood of fathers following the Stable High trajectory (trend level). Type of disability and problem-focused coping were unrelated to fathers' child-domain stress trajectory group membership.

It was expected that child and family characteristics measured in early childhood, middle childhood and adolescence would discriminate groups of mothers and fathers on stress trajectories. Consistent with hypothesis 4b, negative life events over time correlated with higher levels of parenting stress for some trajectory groups. The child's type of disability distinguished only fathers' parent-domain stress trajectories, lending partial support to the hypothesis. Early childhood indicators of behavior problems, internalizing behaviors in particular, distinguished mothers' and fathers' child- and parent-domain stress trajectories. Parent's use of problem-focused coping in adolescence was only found to distinguish mothers' parent-domain stress trajectories.

**Hypothesis 5. We hypothesize that a positive transition in the young adults (YAs) health care from pediatric or adolescent services to adult services will result in a downward (i.e. beneficial) trajectory in parents' parenting stress and in a positive trajectory in the YA's daily living skills.**

A positive change in health care from pediatric to adult services was operationalized as a transition that occurred from pediatric to adult-oriented care in which the family (and young adult) reported being prepared. We conducted correlations to determine whether or not a transition to adult services related significantly to levels of parents' parenting stress and/or to the daily living skills of the young adults. Then, we conducted subsequent correlations to see whether positive transitions (as measured by preparation to transition) was significantly related to either parenting stress or daily living skills. We also conducted eight separate linear regressions, to see whether transition and/or preparation to transition were statistically significant predictors of maternal or paternal parenting or total stress. For these regressions, we controlled for the same type of stress (maternal versus paternal; parenting versus total) at an earlier time point. None of the regressions were statistically significant, and therefore they are not discussed in the results section below.

At age 23, parents rated 73% of YAs as being in very good or excellent health; parents also indicated that 66.2% of YAs took prescribed medication. By the age of 23, 75.3% of participants saw adult-oriented healthcare providers, and 20.5% of participants still saw their pediatricians. In relation to those who had made a transition to an adult-oriented physician, 38% did so at ages 15-18, 34% at ages 19-21, and 28% at ages 22-23. Parents reported that 79.2% of YAs were prepared to make the transition, 11.3% were somewhat prepared, and 9.4% were not prepared. For 21.6% of families, the health care provider offered assistance, such as making a referral, in the transition. Parents reported the following to be helpful during the transition from a pediatric to an adult-oriented health provider: a pediatrician (11%), an insurance company (12.3%), other parents (15%), school personnel (17.8%), and a non-profit organization (19.2%). In addition, parents reported that 35.1% of the YAs in this sample are not able to take responsibility for their own health care needs.

Higher daily living scores for the YAs at each of the four time points (10, 15, 18, and 23) were statistically significantly correlated with greater preparation for this transition from pediatric to adult-oriented health providers ( $p < .05$  at each time point). Daily living scores were not statistically significantly related to whether or not the young adults had transitioned from pediatric to adult-oriented service providers, however. Similarly, levels of parental stress did not statistically significantly correlate with whether or not the young adults had made the transition. However, mothers who had reported higher levels of maternal parenting stress at two time points (ages 15 and 18) also reported being less prepared for this transition ( $p < .05$ ).

Logistical regressions were conducted to determine whether certain family and/or YA characteristics increased the likelihood of a successful transition from pediatric to adult-oriented health care services. Specifically, we looked at the following family and YA characteristics: gender of YA, number of older siblings, family income, maternal education, YA's behavior problems, maternal rating of YA's overall health, maternal rating of the extent to which YA has a limited ability to do other things that YA's peers can do, and YA's daily living skills. Consistent with our previous findings, higher daily living skills of the YA increased the likelihood that the family was prepared for the transition to an adult-oriented service provider (Exp B)=1.040,  $p = 0.018$ ). Behavior problems at age 23 approached but did not reach statistical significance ( $p = 0.053$ ), with higher levels of YA behavior problems decreasing the likelihood of being prepared for the transition. None of the other family or YA characteristics reached statistical significance. Also consistent with our previous findings, none of the family or YA characteristics statistically significantly related to the likelihood of having made the transition.

In addition to these logistical regression analyses, we conducted correlations in order to determine whether indicators of young adults' participation in their own health care were statistically significantly related to likelihood of transition or preparation to transition. These indicators of young adults' participation in their own health care included answers to the following questions, which were asked of primary caregivers: Does YA take responsibility for his/her own health care needs? (If able), has a health care provider encouraged YA to take responsibility for his/her health care?

Young adult responsibility for health care needs was statistically significantly correlated with preparation to transition, with more responsibility related to more preparation ( $r = 0.37$ , and  $p = 0.007$ ). Similarly, encouragement from health care providers was statistically significantly correlated with preparation for this transition, with more encouragement related to more preparation ( $r = 0.31$ , and  $p = 0.043$ ). Neither indicator of health care participation was statistically significantly correlated with the likelihood of making the transition from pediatric to adult providers.

Finally, we conducted correlations to determine whether indicators of young adults' participation in their health care were statistically significantly related to YA or caregiver characteristics. There were no statistically significant relationships with YA behavior problems, or with parental stress. However, higher Vineland scores (i.e., functional skills) were statistically significantly correlated with both indicators of young adults' participation in their health care. Higher scores were related to more responsibility ( $r = .77$ , and  $p < 0.001$ ). Higher scores were also related to more encouragement from providers to take responsibility ( $r = .59$ , and  $p < 0.001$ ).

**Hypothesis 6. We hypothesize that a positive transition for the YA from secondary school to productive daily activities (i.e., employment, postsecondary education, vocational services, adult activity services) will be associated with a positive shift upwards of the trajectory in YA social skills and a shift downward in the trajectory parents' parenting stress.**

A positive transition for the YA from secondary school to productive daily activities was operationalized as the YA's main daily activity being employment or post-secondary school (as reported by mothers). We found that the primary daily activity for the YAs was as follows: 9 % of YAs were engaged in postsecondary education, 43.8% were employed at least part-time, 11.2% were volunteering, 31.5% were attending adult day programs and 4.5% had no specific daily activity. Preliminary analyses were conducted using logistic regression and indicated no significant differences for YA's positive transition by YA type of disability, gender, or socioeconomic status (SES) (OR = 1.5, OR = 1.26, OR = 1.06 for gender, YA type of disability, and SES respectively, all  $p > .05$ ). Analyses did reveal a significant difference for YA's positive transition by YA adaptive functioning (OR = 1.053,  $p < .001$ ). YA's with higher levels of adaptive functioning (measured by the Vineland Adaptive Behavior Scales – Interview Form) were more likely to have a positive transition. Analyses also revealed a significant difference for YA's positive transition by whether or not parents had met with school personnel prior to the transition from secondary school (OR = .215,  $p < .05$ ). Those YAs whose parents met with school personnel prior to the transition from secondary school were more likely to have a positive transition.

In regards to parent responses, 61.5% of mothers reported that they were very satisfied with their YA's current daily activities, while only 44% of fathers reported being very satisfied; 29.5% of mothers reported being somewhat satisfied and 6.4% reported being dissatisfied, 44% of fathers reported being somewhat satisfied and 2% reported being dissatisfied. In regards to the transition process, 56.7% of mothers reported being very satisfied with the process, 29.2% reported being somewhat satisfied with the process, and 11.9% reported being dissatisfied with the process. Despite low levels of dissatisfaction with the YA's current activities, almost half (42%) of mothers reported that they themselves had needed to make changes in their daily lives (such as reducing their hours of employment) because of the YA's transition.

The main hypotheses were tested using OLS linear regression, with separate models for mothers, fathers, and young adults. In the final model, for YA social skills, YA's positive transition predicted 28% of the variance in YA social skills (measured by the Vineland Adaptive Behavior Scales – Interview Form) ( $\beta = .531$ ,  $p < .001$ ). YAs who had a positive transition from secondary school to productive daily activities had higher levels of social skills.

In the final model, for maternal stress, YA's positive transition did not significantly predict changes in total maternal stress ( $\beta = .194$ ,  $p = .219$ ) or maternal stress related to the parent-YA relationship ( $\beta = .095$ ,  $p = .381$ ) from age 18 to age 23. In the final model, for paternal stress, YA's positive transition did not significantly predict changes in paternal parenting stress ( $\beta = -.027$ ,  $p = .825$ ), paternal stress related to the parent-YA relationship ( $\beta = .053$ ,  $p = .632$ ), or total paternal stress ( $\beta = .088$ ,  $p = .459$ ).

**Hypothesis 7. We hypothesize that a positive transition for the YA from home to an independent living situation will be associated with a shift downward in YA behavior problems and a shift upward in YA daily living skills.**

This hypothesis was tested using a hierarchical regression analysis with separate parallel models to examine change in behavior problems and change in daily living skills. A positive transition was operationalized as the YA having lived independently for at least 6 months and his/her mother/father being at least moderately satisfied with the process of that transition. Only 22% of the YAs had made a successful transition from home to independent living by age 23.

Correlational analyses indicated that those YAs with higher adaptive behavior skills made more positive transitions ( $r=.24, p<.05$ ). Preliminary analyses examining type of disability (Down syndrome or other DD), gender and their interaction indicated no significant differences in change in behavior problems ( $F=.0002, F=.230$  and  $F=2.814$ , all  $p>.05$  for type of disability, gender and their interaction respectively) or change in daily living skills ( $F=1.649, F=.639$ , and  $F=.712$ , all  $p>.05$  for type of disability, gender and their interaction, respectively).

Change in behavior problems from age 18 to age 23 was regressed on positive transition to independent living (0=did not have a positive transition, 1=positive transition). Contrary to our hypothesis, positive transition to independent living was not a significant predictor of change in behavior problems ( $\beta =1.462, p>.05$ ). Change in daily living skills from age 18 to age 23 was regressed on positive transition to independent living. Contrary to our hypothesis, positive transition to independent living was not a significant predictor of change in daily living skills ( $\beta =7.601, p>.05$ ).

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

### **A. Conclusions**

Two sets of conclusions can be drawn from this investigation: (1) conclusions related to differences in longitudinal trajectories of children's behavior and skills and of parents adaptation and (2) conclusions related to transitions made by young adults with DD. Each is discussed briefly here.

First, the findings of this study revealed that unique trajectories of the development of children with DD can be empirically determined. Predictors of the different trajectories were found for the three aspects of development examined (daily living skills, social skills, and behavior problems). Although trajectories in the daily living skills and social skills of children with DD were predicted extensively by children's cognitive performance, trajectories of children's behavior problems differed based on type of disability and dimensions of family processes. Differences were found by type of disability as children with motor impairment, in particular, were more likely to display moderate increasing trajectories of internalizing behaviors over time. In addition, in relation to internalizing behavior problems, more adaptive trajectories for all participants were related to positive parenting efficacy during adolescence. In relation to externalizing behavior problems, more adaptive trajectories were related to family cohesion during early childhood and to parenting efficacy during adolescence. Thus, these findings underscore the importance of parenting and family processes in setting children on paths of more adaptive or deleterious trajectories of behavior problems.

The findings in relation to trajectories in parenting stress of both mothers and fathers in this study revealed the importance of negative life events (i.e., events unrelated to having a child with DD) on parenting stress. Negative life events correlated with parenting stress for both mothers and fathers over time. In relation to children's characteristics, children's internalizing (but not externalizing) behavior problems related to more deleterious trajectories of parenting stress. In addition, mothers (but not fathers) who reported more often employing problem-focused types of coping tended to be on more adaptive trajectories of stress. Thus, these findings suggest that raising a child with DD does not necessarily impose a deleterious trajectory of parenting stress on mothers and fathers but that stressors on the family (such as going into debt, marital separation, legal problems) influence overall parenting stress. When children exhibit high levels of internalizing behavior problems, both mothers and fathers are more likely to follow more disadvantageous trajectories of parenting stress. The coping skills of mothers in particular, however, may lead them to more adaptive pathways of parenting stress.

Second, we examined three transitions that YAs were expected to make. In relation to transitions from pediatric to adult health care providers, we found that two thirds of YAs had made that transition by age 23. Although the majority of families whose YA had made the transition reported that the YA was well prepared for this transition, we found that when YAs had higher levels of daily living skills and their parents had lower levels of parenting stress, the YAs were better prepared for the transition. In relation to the transition from secondary school to productive daily activities, we found that the majority of YAs were either employed (43.8%) or attending an adult day program (31.5%). Parents rated the success with this transition, and we found that the transition was rated more positively when the YA had a higher level of daily living skills and when parent(s) had met with school personnel prior to the transition. Finally, in relation to a third transition studied, from living at home to living independently, we found that few YAs (22%) had made that transition by age 23 but that higher adaptive skills related to a more positive transition.

## **B. Limitations**

This investigation has several limitations. First, the sample of participants was originally from the Northeast and was recruited to represent the population of children and families receiving EI services at the time of initial recruitment (1984). The sample is largely of Euro-American background and of moderate to high income, although approximately 20% of families report low levels of income. Moreover, the types of disabilities represented in this sample do not represent the current composition of disabilities served in EI programs, due to the increased diversity of families enrolled in EI (Hebbeler et al., 2001) and to the increase in young children diagnosed with autism spectrum disorder (ASD) (Hauser-Cram et al., in press). Second, some of the findings of this investigation, especially those related to parenting and family processes, are based on parent report and thus, may be influenced by shared variance issues. Many of the child measures, however, are based on direct examination or observation. Finally, a group of the child/YA participants in this study were not able to directly respond to questions or complete measures (34%) because of their low level of functional skills. Although we have parent report on those skills, direct assessment did not result in reliable findings.

### C. Comparison with findings of other studies

The findings from this study add considerable information to other studies in which the relation between family processes and children's behavior problems have been analyzed. Although the development of distinct trajectories and the study of behavior problems over such a long period of time make this investigation unique, the findings contribute to those of other studies in which family processes in relation to the behavior problems of children with DD have been investigated (e.g., Baker, Blacher, & Olsson, 2005). Prior studies, however, have focused on the childhood years; this investigation extends the findings about the role of parenting and family processes in relation to children's behavior problems from early childhood through young adulthood.

In relation to parent adaptation, our findings underscore the importance of other events in the family in relation to parenting stress. Many prior studies have made the assumption that parenting a child with a DD is stressful but few have examined other stressors on the family. Most studies on parenting stress for mothers and fathers raising a child with DD have concentrated on the early childhood years (e.g., Gerstein, Crnic, Blacher, & Baker, 2009; Most, 2006). Our prior analyses on the EICS sample through age 10 revealed increasing trajectories of stress from early to middle childhood (Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001). One important finding from the current study is that for most parents, the highest levels of stress occurred during the middle childhood period. One prior study (Orr et al., 1993) also found higher levels of parenting stress during middle childhood, but that study was cross-sectional, not longitudinal, in design. One reason for the peak of parenting stress in the middle childhood years may relate to high levels of loneliness found for children with DD during middle childhood (Howell, Hauser-Cram, & Kersh, 2007). It is possible that parents may experience stress in relation to children's loneliness as this may reflect fewer sources of support for parents. Our findings about the role of children's internalizing behavior problems in relation to parenting stress are consistent with prior studies that indicate behavior problems, rather than cognitive limitations, account for differences in the well-being of parents of children with DD (Hastings et al., 2005).

Although there is a growing literature on the transitions of young adulthood made by individuals with DD, that literature is still somewhat limited (Osgood et al., 2005). Indeed, the gulf between the two systems of health care (pediatric and adult) has been repeatedly noted (Lotstein, Ghandour, Cash, McGuire, Strickland, & Newachek, 2009). Most of the YAs in this study had made the transition from pediatric to adult health care services as recommended by the American Academy of Pediatrics. Other studies have found that a lack of coordination within the health care system hinders the transition process (Davies, Rennick, & Majnemer, 2011; Scal & Ireland, 2005), and the low levels of assistance from pediatricians noted in this investigation is consistent with prior findings (Pickler, Kellar-Guenther, & Goldson, 2011). In relation to the transition from secondary school to meaningful daily activities, our findings indicate that the majority of YAs had made that transition by age 23, with almost half of the sample employed (at least part time) or volunteering and another third of the sample attending day activity programs. According to the Individuals with Disabilities Education Act (2004), transition services should be focused on improving postsecondary outcomes, and our findings indicate that the transition

from secondary school for the YAs in this study was more successful when parents (and when possible, the YA) met with school personnel. Although the role of family members in school meetings about transition has seldom been studied, many educators have written about the importance of parents' role in transition planning (Chambers et al, 2004; Morningstar, Turnbull, & Turnbull, 1995). Finally, the transition from family home to independent living was made by a low proportion of participants in this study. In the face of shrinking state budgets, the proportion of adults with ID who are living in their families home is growing while waitlists for out-of-home placements grow (Davenport & Eidelman, 2008; Rizzolo, et al., 2009). With these trends, families serve the role of “defacto service delivery systems” (Rizzolo, et al., 2009, p.153).

#### **D. Possible application of findings to MCH health care delivery situations**

The application of the findings from this study to MCH health care delivery systems could be made in several directions. First of all, these findings underscore the importance of understanding processes in the family system as they affect the behavior of children with DD and the well-being of parents themselves. Health care providers may benefit from knowing that although many parents of children with DD are adapting well to their parenting role, some may benefit from assistance, especially when additional stressors are placed on the family. Providers may also need to assist parents who are grappling with high levels of children's behavior problems. Although externalizing behavior problems are often the focus on much attention, the findings from this study point to the importance of recognizing internalizing behavior problems and their effects on parenting processes. The American Academy of Pediatrics recommends that mental health screenings be conducted at every doctor visit (Foy & Perrin, 2010). Referrals to interventions are likely to be beneficial especially if those interventions have demonstrated evidence of decreasing parenting stress and reducing child behavior problems (e.g., Roberts et al., 2006).

In relation to health care transition, it appears that focus should be on those YAs who have low levels of daily living skills as their transitions to adult-oriented health care appear to be less positive. Also, as parents of children with DD who have low levels of skill are likely to be guardians and highly involved with the health care transition, it is important that parents be included in transition processes to minimize the stress they experience related to this system change. Based on this investigation, it appears that pediatricians are seldom assisting parents and YAs with this transition. We recommend that MCH encourage pediatricians to be more proactive in assisting youth and their families with this important transition in health care. MCH could provide specific suggestions to the pediatric community, as well as to receiving adult providers, about concrete ways they could make the transition process function more productively.

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

The results of this study have implications for policy regarding the role of service providers and other personnel in the transition process. Parents who met with school personnel around the transition from secondary school reported more satisfaction with the transition process. It is also interesting to note that some parents also found school personnel to be helpful in making the transition from pediatric to adult-oriented health care. Therefore, parents may see school personnel as key to the multiple transitions that occur for YAs with DD. One

implication of these findings is for the health and education systems to work together in transition planning with parents and youth. This may be especially valuable for youth with special health care needs and for those with low levels of daily living skills.

Moreover, although current education policy requires school personnel to develop a transition plan with parents and YAs during the mid-adolescent period, we found that few families experienced this until the year before the transition was to occur. Therefore, beginning the transition process earlier and making sure that parents and youth are aware of their rights and of the various options available to them is likely to produce multiple benefits.

Finally, policymakers need to increase the capacity of the adult service system to offer more independent living opportunities for young adults with DD. Because this population of individuals is living longer than in the past and because chronic stress related to caregiving may result in health-related challenges for family members, a range of options in the community for YAs with disabilities is needed.

## **F. Suggestions for further research**

The pathway from a child's diagnosis to EI services to schooling and eventually to adult services is often filled with challenges for parents, other family members and the child as well. Each transition point has its own set of specific concerns and opportunities related to a child's developmental skills, a family's adaptive and promotive processes and the service systems' responsiveness and availability. In relation to the transition to adulthood of those with DD, further research would be beneficial if it would consider how the various service systems could work together so that parents are not the lone and "defacto" case managers and so that parents' daily lives and activities are not so disrupted by this transition point. Another critical research question should focus on ways in which postsecondary opportunities could be better developed for young adults with DD. According to recent advances in developmental theory, the needs of the 18-25 age group are unique (Arnett, 2011). Many of the desires of typically developing young adults, such as for friendships, meaningful employment, and further education, are also desires of youth with DD. Expanding opportunities for youth with DD is imperative. For example, some community colleges are beginning to consider ways of serving this population (Griffin, McMillan, & Hodapp, 2010), and such services need to be created with sufficient involvement by family members and youth themselves to ensure that perceived barriers are removed. Related to health care provision, further research is needed on how those with DD in this age group can better understand their own health care needs and advocate for appropriate health care for themselves. In relation to development of the youth themselves, closer examination of the internalizing behavior problems of children with DD would be valuable. Externalizing behavior problems often receive much attention, but internalizing behavior problems appear to have critical effects on parenting processes and may require specific types of intervention. Empirical evidence is needed on ways to decrease internalizing behavior problems in children with DD. Such research is likely to benefit the mental health and well-being of both youth and their families.

## References

- Abidin, R. R. (1995). *Parenting stress index: Manual* (3<sup>rd</sup> ed.). Odessa, FL: Psychological Assessment Resource.
- Achenbach, T.M. (1991). *Manual for the child behavior checklist – 4-18 and 1991 profile*. Burlington, VT: University of Vermont, Department of Psychiatry.
- Achenbach, T. M., & Edelbrock, C. S. (1983). *Manual for the child behavior checklist and revised child behavior profile*. Burlington, VT: University Associates in Psychiatry.
- Achenbach, T.M., & Rescorla, L.A. (2003). *Manual for the ASEBA adult forms & profiles*. Burlington, VT: University of Vermont, Research Center for Children, Youth, and Families.
- American Academy of Pediatrics. (2002). A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics, 110*, 1304-1306.  
doi: 10.1542/peds.110.6.S1.1304
- Arnett, J.J. (2001). *Adolescence and emerging adulthood: A cultural approach* (2<sup>nd</sup> ed.). Auckland, New Zealand: Pearson Education New Zealand.
- Arnett, J.J. (2011). *Bridging cultural and developmental approaches to psychology: New syntheses in theory, research, and policy*. New York, New York: Oxford University Press.
- Baker, B.L., Blacher, J., & Olsson, M.B. (2005). Preschool children with and without developmental delay: Behaviour problems, parents' optimism and well-being. *Journal of Intellectual Disability Research, 49*(8), 575-590. doi: 10.1111/j.1365-2788.2005.00691.x
- Baltes, P.B., Reese, H.W., & Lipsitt, L.P. (1980). Life-span developmental psychology. *Annual Review of Psychology, 31*, 65-110. doi: 10.1146/annurev.ps.31.020180.000433

- Bayley, N. (1969). Behavioral correlates of mental growth: Birth to thirty-six years. *American Psychologist*, 23, 1-17.
- Bengtson, V. L., & Schrader, S. S. (1990). Parent-child relations. In J. Touliatos, B.F. Perlmutter, & M.A. Strauss (Eds.), *Handbook of family measurement techniques* (pp. 115-133). Newbury Park: Sage.
- Brandt, P.A., & Weinert, C. (1981). The PRQ: A social support measure. *Nursing Research*, 30(5), 277-280. doi: 10.1097/00006199-198109000-00007
- Buhrmester, D., & Furman, W. (1990). Perceptions of sibling relationships during middle childhood and adolescence. *Child Development*: 61(5), 1387-1398. doi: 10.2307/1130750
- Center for Disease Control and Prevention, National Center for Health Statistics. State and Local Area Integrated Telephone Survey, National Survey of Children with Special Health Care Needs. Available at [http://www.cdc.gov/nchs/data/slait/cshcn2005\\_english.pdf](http://www.cdc.gov/nchs/data/slait/cshcn2005_english.pdf). Accessed July 11, 2006.
- Chambers, C.R., Hughes, C., & Carter, E.W. (2004). Parent and sibling perspectives on the transition to adulthood. *Education and Training in Developmental Disabilities*, 39(2), 79-94.
- Davenport, T.N., & Eidelman, S.M. (2008). Affordability of family care for an individual with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 46(5), 396-399. doi: 10.1352/2008.46:396-399
- Davies, H., Rennick, J., & Majnemer, A. (2011). Transition from pediatric to adult health care for young adults with neurological disorders: Parental perspectives. *Canadian Journal of Neuroscience Nursing*, 33(2), 22-29.

- Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior, 21* (3), 219-239. doi:10.2307/2136617
- Foy, J.M., & Perrin, J. (2010). Enhancing pediatric mental health care: Strategies for preparing a community. *Pediatrics, 125*, S75- S86.
- Frank, S. J., Jacobson, S., & Hole, C. (1986). The parenting alliance: Bridging the relationship between marriage and parenting. Unpublished manuscript, Michigan State University.
- Gerstein, E.D., Crnic, K.A., Blacher, J., & Baker, B.L. (2009). Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. *Journal of Intellectual Disability Research, 53*(12), 981-997. doi: 10.1111/j.1365-2788.2009.01220.x
- Griffin, M.M., McMillan, E.D., & Hodapp, R.M. (2010). Family perspectives on post-secondary education for students with intellectual disabilities. *Education and Training in Autism and Developmental Disabilities, 45*(3), 339-346.
- Gorall, D.M., Tiesel, J., & Olson. (2006). FACES IV: Development and validation. Retrieved July 13, 2006, from <http://www.facesiv.com/home.html>
- Hastings, R.P., & Beck, A. (2004). Practitioner review: Stress intervention for parents of children with intellectual disabilities. *Journal of Child Psychology and Psychiatry, 45*(8), 1338-1349. doi: 10.1111/j.1469-7610.2004.00357.x
- Hastings, R.P., Kovshoff, H., Ward, N.J., degli Espinosa, F., Brown, T., & Remington, B. Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders, 35*(5), 635-644. doi: 10.1007/s10803-005-0007-8

- Hauser-Cram, P., Cannarella, A., Tillinger, M. & Woodman, A. C. (in press). Disabilities and development. In R. M. Lerner, A. Easterbrooks, & J. Mistry (Vol. Eds.), *Handbook of psychology, Vol. 6, Developmental psychology* (2<sup>nd</sup> ed.). Hoboken, NJ: Wiley.
- 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).
- Hebbeler, K. M., Wagner, M., Spiker, D., Scarborough, A., Simeonsson, R., & Collier, M. (2001). *The National Early Intervention Longitudinal Study: A first look at the characteristics of children and families entering early intervention* (NEILS Data Report No. 1). Menlo Park, CA: SRI International.
- Howell, A., Hauser-Cram, P., & Kersh, J. (2007). Setting the stage: Early child and family characteristics of later loneliness in children with developmental disabilities. *American Journal on Mental Retardation, 112*, 18-30. doi:10.1352/0895-8017(2007)112[18:STSECA]2.0.CO;2
- Jones, B.L., Nagin, D.S., & Roeder, K. (2001). A SAS procedure based on mixture models for estimating developmental trajectories. *Sociological Methods & Research, 29*(3), 374-393.
- Kraemer, B. R., & Blacher, J. (2001). Transition for young adults with severe mental retardation: School preparation, parent expectations, and family involvement. *Mental Retardation, 39* (6), 423-435. doi: 10.1352/00476765(2001)039<0423:TFYAWS>2.0.CO;2

- Lerner, R.M. (1991). Changing organism-context relations as the basic process of development: A developmental contextual perspective. *Developmental Psychology, 27*(1), 27-32. doi: 10.1037/0012-1649.27.1.27
- Lotstein, D.S., Ghandour, R., Cash, A., McGuire, E., Strickland, B., & Newacheck, P. (2009). Planning for health care transitions: Results from the 2005-2006 national survey of children with special health care needs. *Pediatrics, 123*, 145-152.
- Luther, S.S., Cicchetti, D., & Becker, B. (2000). The construct of resilience: A critical evaluation and guidelines for future work. *Child Development, 71*, 543-562. doi: 10.1111/1467-8624.00164
- McCarthy, D. (1972). *McCarthy scales of children's abilities*. Cleveland, OH: Psych.Corp.
- Morgan, G.A., MacTurk, R.H., & Hrcir, E.J. (1991). Mastery motivation: Overview, definitions, and conceptual issues. In R.H. MacTurk & G.A. Morgan, (Eds.), *Mastery motivation: Origins, conceptualizations, and applications* (pp. 1-18). Norwood, New Jersey: Ablex Publishing Corporation.
- Morningstar, M.E., Turbull, A.P., & Turnbull, H.R. (1995). What do students with disabilities tell us about the importance of family involvement in the transition from school to adult life? *Exceptional Children, 62*(3), 249-260.
- Most, D.E., Fidler, D.J., Laforce-Booth, C., & Kelly, J. (2006). Stress trajectories in mothers of young children with Down syndrome. *Journal of Intellectual Disability Research, 50*(7), 501-514. doi: 10.1111/j.1365-2788.2006.00796.x
- Nagin, D.S. (1999). Analyzing developmental trajectories: A semiparametric, group-based approach. *Psychological Methods, 4*(2), 139-157. doi: 10.1037/1082-989X.4.2.139

- Nagin, D.S. (2005). *Group-based modeling of development*. Cambridge, MA: Harvard University Press.
- Orr, R.R., Cameron, S.J., Dobson, L.A., & Day, D.M. (1993). Age-related changes in stress-experienced by families with a child who has developmental delays. *Mental Retardation*, *31*(3), 171-176.
- Osgood, W., Foster, E.M., Flanagan, C., & Ruth, G.R. (2005). *On your own without a net: The transition to adulthood for vulnerable populations*. Chicago, IL: University of Chicago Press.
- Pickler, L., Kellar-Guenther, Y., & Goldson, E. (2011). Barriers to transition to adult care for youth with intellectual disabilities. *International Journal of Child and Adolescent Health*, *3*(4), 575-584.
- Reiss, J.G., Gibson, R.W., & Walker, L.R. (2005). Health care transition: Youth, family, and provider perspectives. *Pediatrics*, *115*(1), 112-120.
- Rizzolo, M.C., Hemp, R., Braddock, D., & Schindler, A. (2009). Family support services for persons with intellectual and developmental disabilities: Recent national trends. *Intellectual and Developmental Disabilities*, *47*(2), 152-155. doi: 10.1352/1934-9556-47.2.152
- Roberts, C., Mazzucchelli, T., Studman, L., & Sanders, M.R. (2006). Behavioral family intervention for children with developmental disabilities and behavioral problems. *Journal of Clinical Child and Adolescent Psychology*, *35*(2), 180-193. doi: 10.1207/s15374424jccp3502\_2
- Rogosa, D., Brandt, D., & Zimowski, M. (1982). A growth curve approach to the measurement of change. *Psychological Bulletin*, *92*(3), 726-748. doi: 10.1037/0033-2909.92.3.726

- Roid, G.H. (2003). *Stanford Binet intelligence scales* (5th ed.). Itasca, IL : Riverside Pub.
- Scal, P., & Ireland, M. (2005). Addressing transition to adult health care for adolescents with special health care needs. *Pediatrics*, *115*(6), 1607-1612.
- Schafer, J.L. (2001). Multiple imputation with PAN. In L.M. Collins & A.G. Sayer (Eds.), *New methods for the analysis of change* (pp. 357-377). Washington, DC: American Psychological Association.
- Sparrow, S., Balla, D., & Cicchetti, D. (1984). *Vineland adaptive behavior scales. Expanded form manual*. Circle Pines, MN: American Guidance Service.
- Sparrow, S.S., Cicchetti, D.V., & Balla, D.A. (2005). *Vineland-II*. Circle Pines, MN: American Guidance Service.
- Sameroff, A. J., (1995). General systems theories and developmental psychopathology. In D, Cicchetti & D.J. Cohen (Eds.), *Developmental psychopathology* (pp. 659-695). New York: Wiley.
- Sheras, P.L., Abidin, R.R., Konold, T.R. (1998). *Stress index for parents of adolescents: Professional manual*. Odessa, FL: Psychological Assessment Resources.
- Thorndike, R., Hagen, E., & Sattler, J. (1986). *Stanford-Binet intelligence scale* (4<sup>th</sup> ed.). Chicago: The Riverside Publishing Company.
- Tonge, B. (1999). Psychopathology of children with developmental disabilities. In N. Bouras (Ed.), *Psychiatric and behavioral disorders in developmental disabilities and mental retardation* (pp. 157-174). NY: Cambridge U. Press.
- Wehmeyer, M.L., & Garner, N.W. (2003). The impact of personal characteristics of people with intellectual and developmental disability on self-determination and autonomous

functioning. *Journal of Applied Research in Intellectual Disabilities*, 16(4), 255-265.

doi: 10.1046/j.1468-3148.2003.00161.x

Williams, G.A., & Asher, S.R. (1992). Assessment of loneliness at school among children with mild mental retardation. *American Journal on Mental Retardation*, 97(4), 373-385.

Zigler, E., Bennett-Gates, D., Hodapp, R., & Henrich, C. C. (2002). Assessing personality traits of individuals with mental retardation. *American Journal on Mental Retardation*, 107(3), 181-193. doi: 10.1352/0895-8017(2002)107<0181:APTOIW>2.0.CO;2

## VI. List of Products

### Journal Articles:

Woodman, A. C., & Hauser-Cram, P. (in press). The role of coping strategies in predicting change in parenting efficacy and depressive symptoms among mothers of adolescents with developmental disabilities. *Journal of Intellectual Disability Research*  
doi:10.1111/j.1365-2788.01555.xR.

Mitchell, D.B., & Hauser-Cram, P. (2010). Early childhood predictors of mothers' and fathers' relationships with adolescents with developmental disabilities. *Journal of Intellectual Disability Research*, 54, 487-500. doi: 10.1111/j. 1365-2788.2010.01268.x

Cuskelly, M., Hauser-Cram, P., & Van Riper, M. (2009). Families of children with Down syndrome: What we know and what we need to know. *Down Syndrome: Research and Practice*, 12, 202-210.

Mitchell, D.B., & Hauser-Cram, P. (2009). Early predictors of behavior problems: Two years after early intervention. *Journal of Early Intervention*, 32, 3-16. doi:  
10.1177/1053815109349113

Mitchell, D.B., & Hauser-Cram, P. (2008). 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*, 29, 97-112. doi:  
10.1016/j.ridd.2006.12.002

### **Book Chapters:**

- Hauser-Cram, P., Cannarella, A., Tillinger, M. & Woodman, A. C. (in press). Disabilities and development. In R. M. Lerner, A. Easterbrooks, & J. Mistry (Vol. Eds.), *Handbook of psychology, Vol. 6, Developmental psychology* (2<sup>nd</sup> ed.). Hoboken, NJ: Wiley.
- Hauser-Cram, P. Howell, A.N., & Young, J.E. (2012). A decade of review of research related to mother-child interaction in families with a child with Down syndrome or Williams syndrome. In J. Burack, B. Hodapp, & E. Zigler (Eds.), *Handbook of mental retardation and development* (2<sup>nd</sup> ed). Cambridge, UK: Cambridge University Press.
- Hauser-Cram, P., Howell-Moneta, A.N., Young, J.M. (2011). Dyadic interactions between mothers and children with Down syndrome or Williams syndrome: Empirical evidence and emerging agendas. In J.A. Burack, R.M. Hodapp, G. Iarocci & E. Zigler (Eds.), *Oxford handbook of intellectual disabilities and development* (2<sup>nd</sup> ed., pp. 318-333). New York, New York: Oxford University Press.
- Hauser-Cram, P., & Warfield, M.E. (2011). Early intervention services. In W.B. Carey, A. Crocker, et al., (Eds.) *Developmental-behavioral pediatrics* (4<sup>th</sup> ed). Philadelphia: Elsevier.
- Hauser-Cram, P., Warfield, M.E., Shonkoff, J.P., Krauss, M.W., Sayer, A., & Upshur, C.C. (2010). Children with disabilities: A developmental-contextual perspective. In H.B. Weiss, H. Kreider, M.E. Lopez, & C. Chapman-Nelson (Eds.), *Preparing educators to engage families* (pp. 7-11). Thousand Oaks, CA: Sage.

Hauser-Cram, P., Krauss, M.W., & Kersh, J. (2009). Adolescents with developmental disabilities and their families. In R.M. Lerner & L. Steinberg (Eds.), *Handbook of adolescent psychology* (pp. 589-617). New York: Wiley.

**Presentations:**

Hauser-Cram, P., Demers, L., & Woodman, A. (2012, August). Early task persistence predicts trajectory skill groups for children with disabilities. Paper to be presented at the American Psychological Association Conference, Orlando, FL.

Woodman, A., & Hauser-Cram, P. (2012, August). Group trajectories of stress across 23 years of parenting a child with a developmental disability. Paper to be presented at the American Psychological Association Conference, Orlando, FL.

Warfield, M.E. (2012). "The Early Intervention Collaborative Study," at the Massachusetts Early Intervention Consortium Meeting (March) Watertown, MA.

Woodman, A., & Hauser-Cram, P. (2012, March). Patterns of stress experienced by parents of children with developmental disabilities. Paper presented at the Multidisciplinary PhD Research Development Day, Chestnut Hill, MA.

Cannarella, A. (2011, April). Predictors of sibling relationship quality in adolescents with developmental disabilities. Symposium presented at the Society for Research on Child Development, Montreal, QC.

Hauser-Cram, P., & Cavender-Wood, H. (2011, November). Issues in practice and evaluation of early intervention services. Leadership Education in Neurodevelopmental and Other Disabilities (LEND) program. The Institute for Community Inclusion, Children's Hospital, Boston, MA. (Invited)

- Mawdsley, H.P. (2011, April). Families of children with developmental disabilities: Parenting stress, child behavior, and the moderating impact of parental coping. Paper symposium presented at the Society for Research on Child Development, Montreal, QC
- Tillinger, M., Woodman, A. C., Cannarella, A., & Hauser-Cram, P. (2011, March). Perceptions of self and family among adolescents with Developmental Disabilities. Paper presented at the Boston College Graduate Student Scholarship Symposium, Chestnut Hill, MA.
- Woodman, A., Tillinger, M., Reid, A., & Hauser-Cram, P. (2011, March). Parenting stress among fathers of children with developmental disabilities: From early childhood through adolescence. Paper presented at the Graduate Scholarship Symposium, Chestnut Hill, MA.
- Woodman, A., Tillinger, M., Reid, A., & Hauser-Cram, P. (2011, March). The role of coping in predicting parenting stress among fathers of children with developmental disabilities. Paper presented at the Graduate Education Association Research Forum, Chestnut Hill, MA.
- Hauser-Cram, P. (2010, March). Findings from a longitudinal study of children with disabilities and their families. Harvard School of Public Health. Boston, MA. (Invited address)
- Mitchell, D. B., & Hauser-Cram, P. (2010, June). Early family environment and the social competence of adolescent children with disabilities. Paper presented at the European Conference on Psychological Theory and Research on Intellectual and Developmental Disabilities (ECIDD) in Geneva, Switzerland.
- Woodman, A., Cannarella, A., Tillinger, M., Reid, A., & Hauser-Cram, P. (2010, March). The importance of marital quality in families with children with disabilities. Paper presented in the Families and Children with DD: Perspective Across the Developmental Period

symposium at the Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities, Annapolis, MD.

Hauser-Cram, P. (2009, July). "Parenting is like nothing you read in a book." Parenting a child with developmental disabilities. The Military Child Conference. Philadelphia, PA. (Invited address).

Hauser-Cram, P. (2009, November). "Sometimes I wish I didn't have this Down syndrome." Perspectives of children with disabilities. Hawke Family Lecture, Child Development Conference, the Hospital for Sick Children, Toronto, Ontario. (Invited keynote address)

Hauser-Cram, P. (2009, November). Using Play and Mastery motivation to assess young children. Hospital for Sick Children, Toronto, Ontario.

Hauser-Cram, P., Erickson, M. E., & Mitchell D. B. (2009, April). Do things get better or worse? Changes in the well-being of fathers of children with developmental disabilities. Paper presented at the Society for Research on Child Development Conference, Denver, CO.

Hauser-Cram, P. & Mawdsley, H.P. (2009, November). Evaluating early intervention. Leadership Education in Neurodevelopmental and Other Disabilities (LEND) program. The Institute for Community Inclusion, Children's Hospital, Boston, MA. (Invited)

Mawdsley, H. P. (2009, April). Parents' perceptions of the transition from early intervention to preschool. Paper presented at the Society for Research on Child Development Conference, Denver, CO.

Hauser-Cram, P. (2008, November). Adolescent to adult transitions: Trepidation or triumph? Some findings from a longitudinal study. Opening Doors State of the Science Conference, Bethesda, MD. (Invited address)

Mitchell, D., & Hauser-Cram, P. (2008, August). Early predictors of paternal relationships with adolescents with developmental disabilities. Paper presented at the American Psychological Association Conference, Boston, MA.

**Posters:**

Cannarella, A., & Hauser-Cram, P. (2012, March). Pessimism and expectations for the future and sibling relationship affective tone in siblings of adolescents with developmental disabilities. Poster presented at the Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities, Annapolis, MD.

Heyman, M., Woodman, A., McMullan, M., Cannavina, M., Cannarella, A., Tillinger, M., & Hauser-Cram, P. (2012, June). Three magic wishes: Insight into the self-perceptions and goals of young adults with developmental disabilities. Poster to be presented at the American Association on Intellectual and Developmental Disabilities Conference, Charlotte, NC.

Heyman, M., Woodman, A. C., Tillinger, M., Cannarella, A., & Hauser-Cram, P. (2012, March). Predicting ratings of adolescent motivation from early childhood indicators: A study of children with developmental disabilities. Poster presented at the Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities, Annapolis, MD.

Mawdsley, H. (2012, March). Parenting stress, child problem behavior, and the influence of social support within families of children with developmental disabilities. Poster presented at the Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities, Annapolis, MD.

Mitchell, D., & Hauser-Cram, P. (2012, March). Partner stress as a contributor to family cohesion in parents of adolescents with disabilities. Poster presented at the Gatlinburg

Conference on Research and Theory in Intellectual and Developmental Disabilities,  
Annapolis, MD.

Woodman, A. (2012, June). The role of family resources and supports in predicting trajectories of stress among parents of children with developmental disabilities. Poster to be presented at the American Association on Intellectual and Developmental Disabilities Conference, Charlotte, NC.

Woodman, A., & Hauser-Cram, P. (2012, March). Group-based trajectories of parenting stress among mothers and fathers of children with developmental disabilities: From infancy through young adulthood. Poster presented at the Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities, Annapolis, MD.

Crossman, M.K., Cannarella, A.M., Rosenfeld, A., & Hauser-Cram, P. (2011, March). Child-related stress and mother-child interactions: The Down syndrome advantage. Poster presented at the Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities, San Antonio, TX.

Mitchell, D., Crossman, M.K., Rosenfeld, A., Comstock, M., & Hauser-Cram, P. (2011, March). Mother-child interactions and maternal acceptance: The Down syndrome advantage. Poster presented at the Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities, San Antonio, TX.

Tillinger, M., Woodman, A. C., Cannarella, A., & Hauser-Cram, P. (2011, March). Perceptions of self and family among adolescents with developmental disabilities. Poster presented at the Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities, San Antonio, TX.

- Woodman, A., Tillinger, M., Cannarella, A., Hauser-Cram, P., Antonucci, R., Comstock, M., Jacobs, H.,...Rosenfeld, A. (2011, March). Parental concerns about the sexuality of their adolescents with developmental disabilities. Poster presented at the Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities, San Antonio, TX.
- Woodman, A., Tillinger, M., Reid, A., & Hauser-Cram, P. (2011, April). Parenting stress among fathers of children with developmental disabilities: From early childhood through adolescence. Poster presented at the Society for Research in Child Development Conference, Montreal, Quebec, Canada.
- Cannarella, A., & Hauser-Cram, P. (2010, March). The role of parent and teen characteristics in depressive symptoms for adolescents with developmental disabilities. Poster presented at the Gatlinburg Conference for Research and Theory on Intellectual and Developmental Disabilities, Annapolis, MD.
- Mawdsley, H.P. (2010, April). The impact of parental coping and social support within families who have children with developmental disabilities. Poster presented at the 2010 Annual Children's National Medical Center Research Day, Washington, D.C.
- Woodman, A., Cannarella, A., Tillinger, M., Reid, A., & Hauser-Cram, P. (2010, June). Early mastery motivation as a predictor of executive function in young adults with developmental disabilities. Poster presented at the American Association on Intellectual and Developmental Disabilities Conference, Providence, RI.
- Woodman, A., Cannarella, A., Tillinger, M., Reid, A., & Hauser-Cram, P. (2010, April). Early mastery motivation as a predictor of executive function in young adults with

developmental disabilities. Poster presented at the Graduate Education Association Academic Research Forum, Chestnut Hill, MA.

Mawdsley, H.P. (2009, April). Parents' perceptions of the transition from early intervention to preschool. Poster presented at the Society for Research on Child Development Conference, Denver, CO.

Mawdsley, H.P. & Crossman, M. (2009, August). Social support of parents of children with developmental disabilities. Poster presented at the Annual American Psychological Association Conference, Toronto, Canada.

Mawdsley, H.P., & Hauser-Cram, P. (2009, March). Parental efficacy as a mediator between behavior and parenting stress. Poster presented at the Gatlinburg Conference for Research and Theory on Intellectual and Developmental Disabilities, New Orleans, LA.

Mitchell, D. B., Cannarella, A., & Hauser-Cram, P. (2009, April). Early mastery motivation as a predictor of later behavior problems in adolescents with developmental disabilities. Poster presented at the Society for Research on Child Development Conference, Denver, CO.

Mitchell, D. B., Cannarella, A., & Hauser-Cram, P. (2009, August). Self-agency's role in the well-being of adolescents with developmental disabilities. Poster presented at the American Psychological Association Conference, Toronto, ON, Canada.

Woodman, A. & Hauser-Cram, P. (2009, August). Coping strategies among parents of children with developmental disabilities. Poster presented at the American Psychological Association Conference, Toronto, ON, Canada.

Woodman, A. & Hauser-Cram, P. (2009, April). Mothers' desire for autonomy for their adolescents with developmental disabilities. Poster presented at the Society for Research on Child Development Conference, Denver, CO.

Woodman, A. & Hauser-Cram, P. (2009, August). Parents' desire for autonomy for their adolescents with developmental disabilities. Poster presented at the American Psychological Association conference, Toronto, ON, Canada.

Mawdsley, H., & Crossman, M. (2008, March). Social support of parents of children with developmental disabilities. Poster presented at the Gatlinburg Conference on Research and Theory in Intellectual and Developmental Disabilities, San Diego, CA.

Mawdsley, H.P., & Hauser-Cram, P. (2008, August). From early intervention to preschool: Parents' views and children's behaviors. Poster presented at the American Psychological Association Conference, Boston, MA.

Pan, H., & Hauser-Cram, P. (2008, March). Social skills, peer acceptance, and loneliness of adolescents with disabilities in inclusive classrooms. Poster presented at the Gatlinburg Conference for Research and Theory in Intellectual and Developmental Disabilities, San Diego, CA.

**Dissertations:**

Cannarella, A. (2012). Sibling relationship quality and future planning in siblings of adolescents with developmental disabilities: A mixed methods approach. (Unpublished doctoral dissertation.) Boston College, Chestnut Hill, MA.

Woodman, A. (2012). Trajectories of parenting stress among mothers and fathers of children with developmental disabilities: From early childhood through adolescence. (Unpublished doctoral dissertation). Boston College, Chestnut Hill, MA.

Mawdsley, H.P. (2010). The transactional relation between child behavior problems and parenting stress and the impact of coping and social support within families who have children with developmental disabilities. Boston College, Chestnut Hill, MA.

**Articles Submitted/Currently Under Review**

Mawdsley, H. P., & Hauser-Cram, P. (submitted) Mothers of young children with disabilities: Perceived benefits and worries about preschool.

**Articles in Preparation/Planned:**

Changes in child problematic behavior and parent stress within families of children with disabilities

Similarities and differences in trajectories of parenting stress among mothers and fathers raising children with disabilities

The importance of marital quality in families with children with disabilities

Sibling relationship quality in adolescents with developmental disabilities: Mother and sibling predictors

Early childhood motivation as a predictor of executive function in young adults with developmental disabilities

Appendix

Figure 1

Trajectories of Internalizing Behavior Problems (N=166)

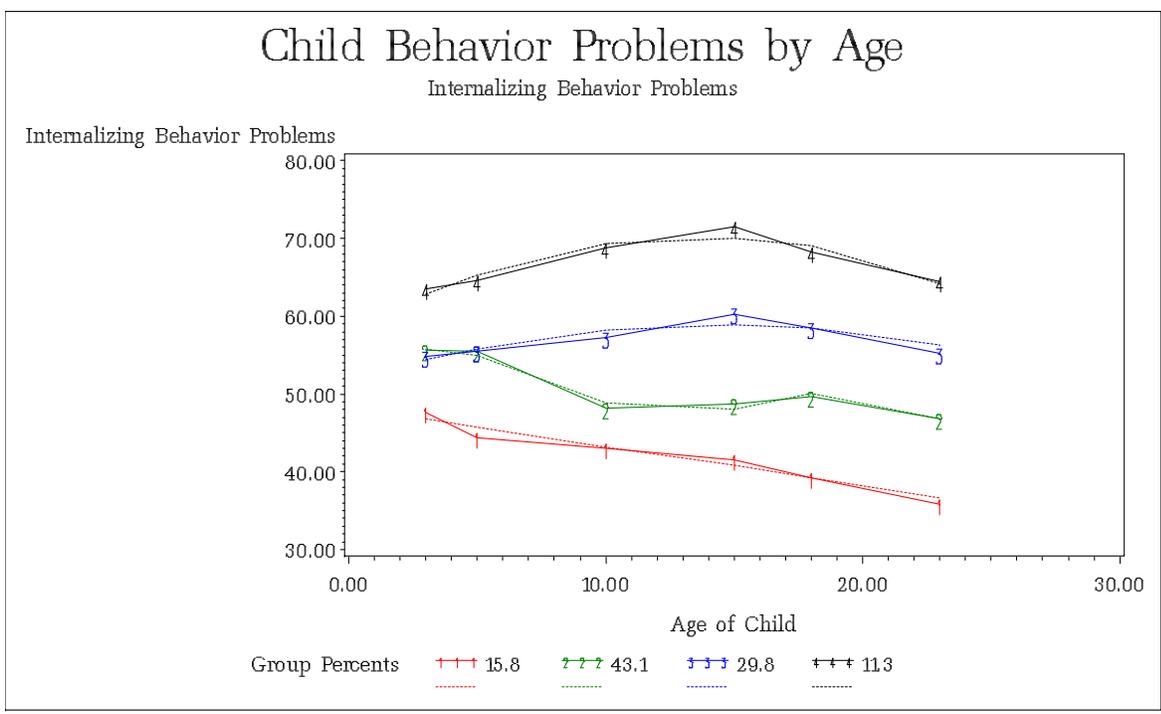


Figure 2

Trajectories of Externalizing Behavior Problems (N=166)

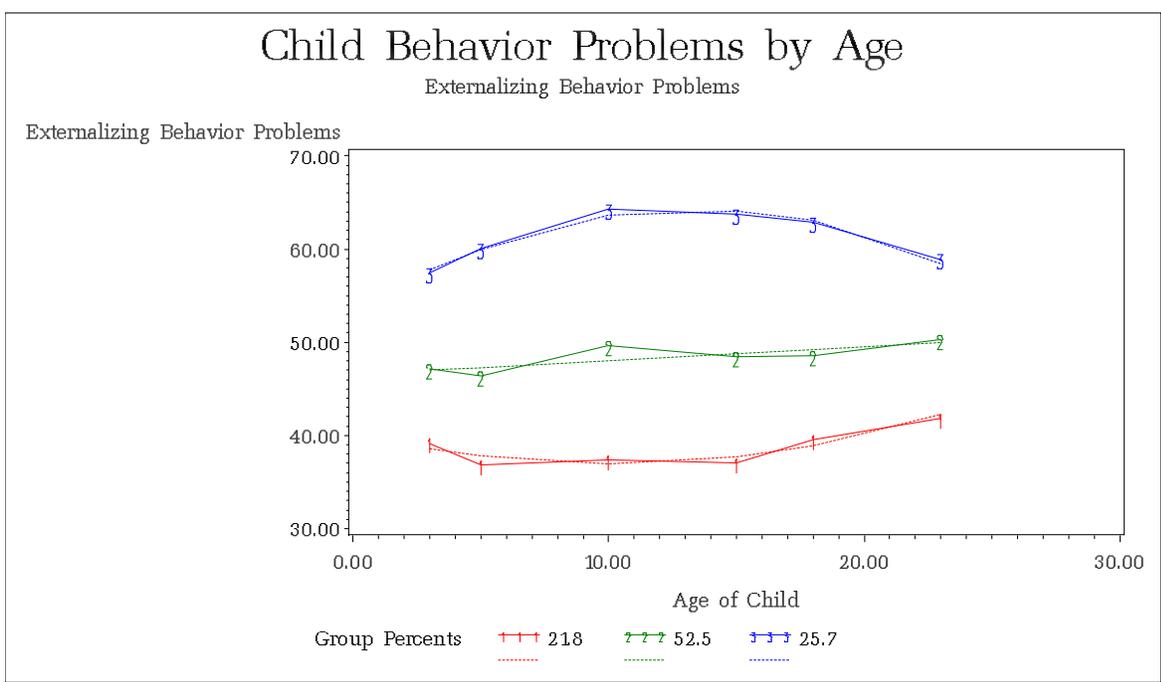


Figure 3

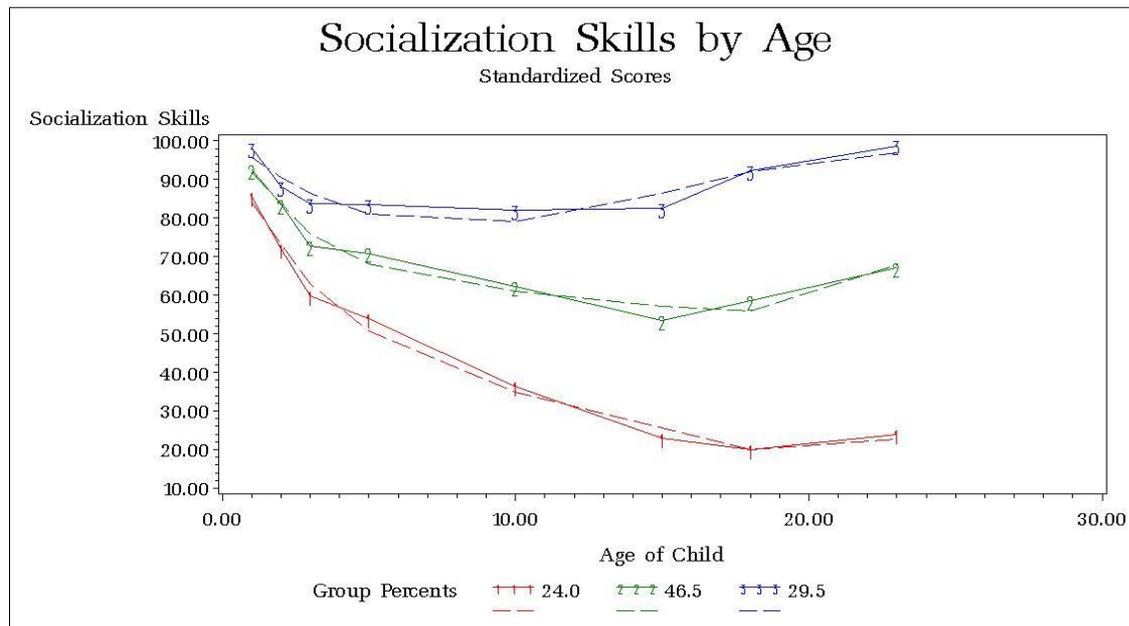
*Trajectories of Social Skills (N=195)*

Figure 4

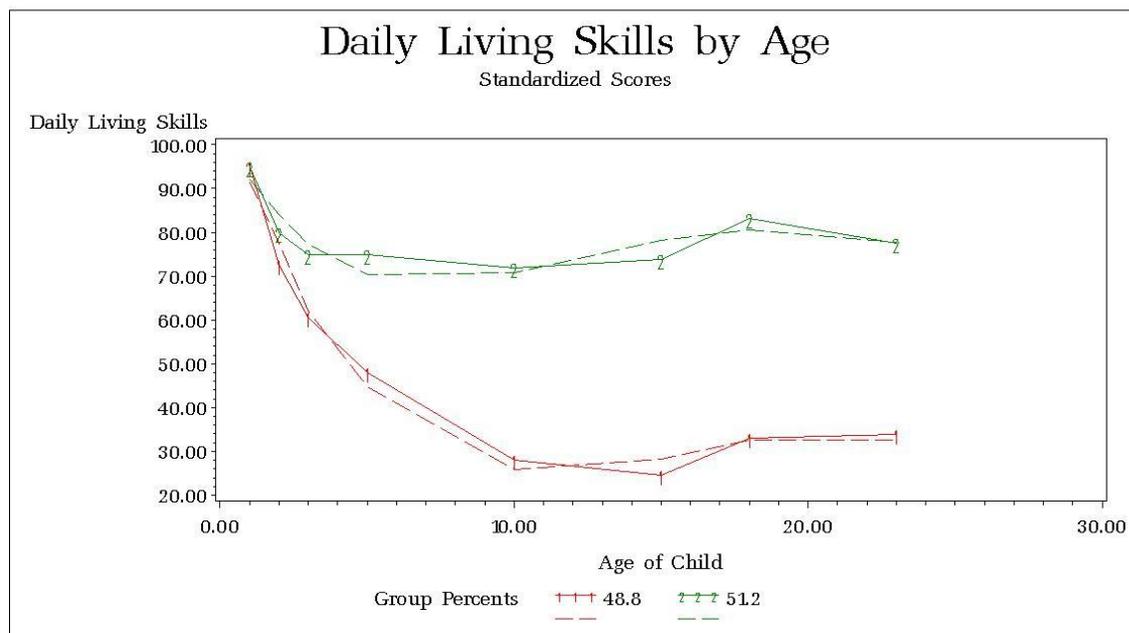
*Trajectories of Daily Living Skills (N=195)*

Figure 5

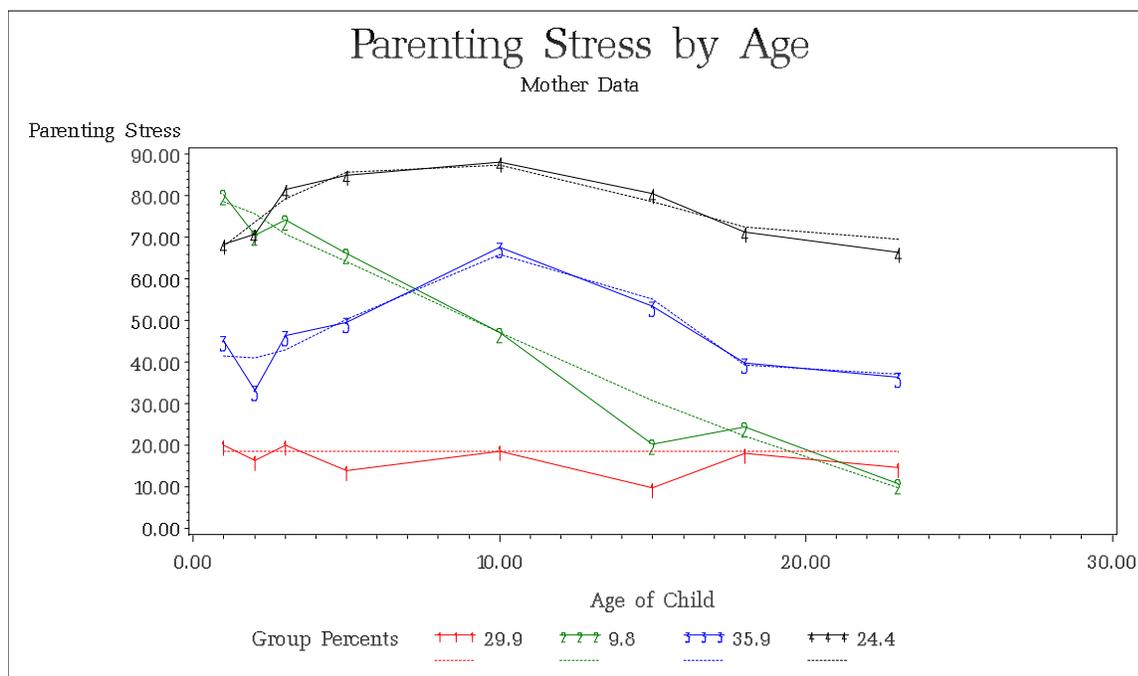
*Trajectories of Maternal Parenting Stress (N=186)*

Figure 6

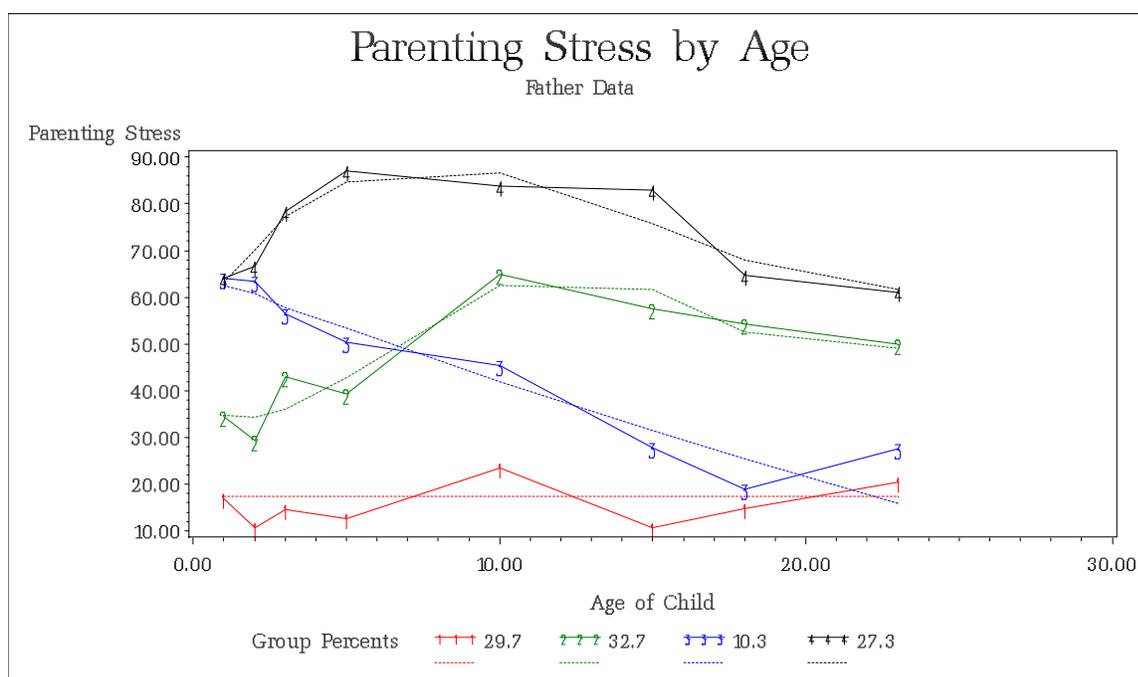
*Trajectories of Paternal Parenting Stress (N=182)*

Figure 7

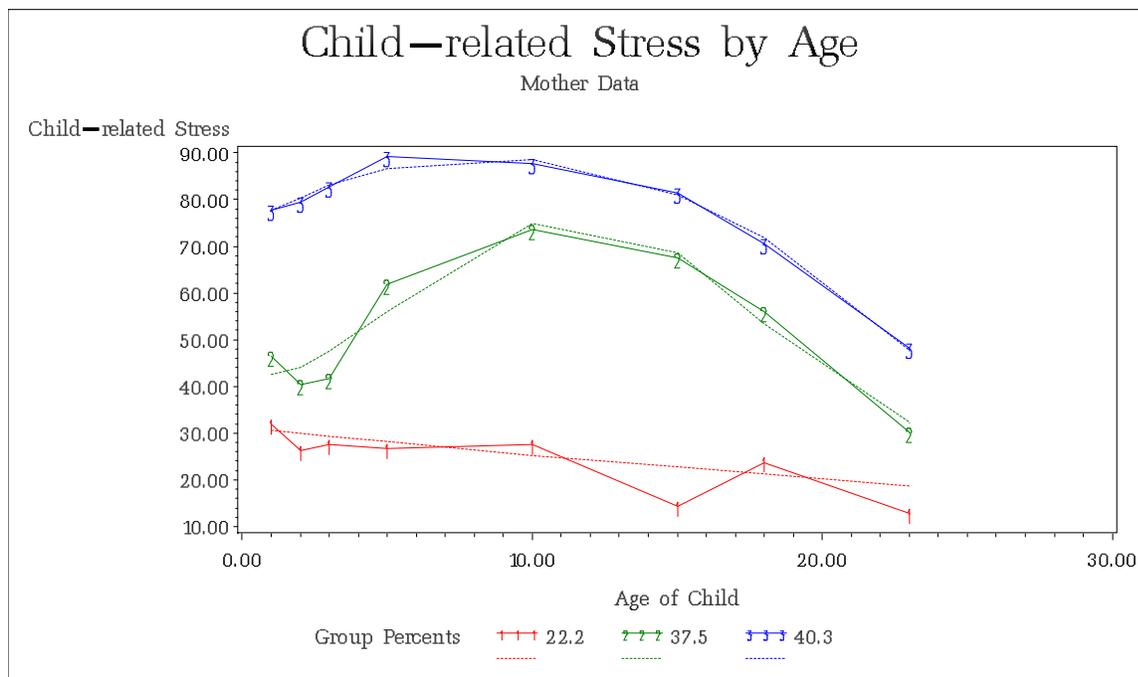
*Trajectories of Maternal Child-Related Stress (N=186)*

Figure 8

*Trajectories of Paternal Child-Related Stress (N=182)*