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EARLY INTERVENTION COLLABORATIVE STUDY (EICS) PHASE IV:
ADOLESCENCE

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Final Report: Executive Summary

R40 MC 00177

Early Intervention Collaborative Study (EICS) Phase IV: Adolescence

Statement of the Problem:

Since 1985, the Early Intervention Collaborative Study (EICS) has investigated the development of over 150 children identified with early developmental delays or disabilities, and the adaptation of their families to the challenges of parenting a child with developmental disabilities. We have also investigated the types, intensity and effects of therapeutic, social, health, and educational services received by children and their families. The current phase of this longitudinal study was designed to investigate both the health and development of these children during mid adolescence and the challenges faced by their parents.

Research Objectives:

This phase of EICS had three primary aims: First, with respect to the adolescents, the project was designed to investigate two developmental issues that are cardinal challenges of this life phase: social connectedness to peers and the emergence of personal autonomy. Second, in terms of the family unit, the adaptation of both mothers and fathers is considered central to adolescent health and development, and thus this investigation extended our focus on parent well-being into the adolescent years. Third, given the range of health care needs of adolescents with developmental disabilities, we examined parents' satisfaction with the health care delivery system for this sample of adolescents with special health care needs.

Study Design and Methods:

The study is a continuation of a non-experimental, longitudinal investigation of a sample of children with early-identified disabilities and their families. Children and families have participated in this study since their entry into early intervention (EI) services during the child's infant or toddler years. Findings from the early childhood phase of the study can be found in Shonkoff et al., (1992), and from the early-to-middle childhood phase in Hauser-Cram et al. (2001).

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

more areas of development with no established diagnosis or etiology that implied a specific diagnosis at the time of entry into EI.

A total of 190 children and families were initially recruited into the study. Attrition has remained at 9-10% between data collection periods. At age 15 a total of 139 adolescents (55 % male) and families continued to participate. Some families (n= 22) chose to not participate in this phase of the study, several families have moved without forwarding addresses or other means of contact (n= 19), and some children have died (n=10). The sample at age 15 consists of 42 adolescents with Down syndrome, 53 with motor impairment, and 44 with developmental delay. Almost 70% of the adolescents live with two parents. Marital status has changed in the last 5 years in 12% of the families. On average, the parents have some education beyond high school (Mean (SD)= 14.2 (2.4) years for mothers, and 13.4 (3.7) years for fathers), although parents have a wide range of educational levels (from 8th grade to graduate school). The adolescents are predominately Euro-American (91.5 %) (1.4 % African-America, 2.9 % Hispanic/Latino, and 2.2 % Asian/other). Average family income is between \$45,000 and \$50,000. In relation to employment, 89% of fathers are employed full-time, 38.2 % of mothers are employed full-time, and 32.8% of mothers are employed part time.

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

Findings:

A set of seven hypotheses were examined during this study phase. Each hypothesis is listed below followed by a brief description of the results.

Hypothesis 1. *Controlling for cognitive skills, adolescent general adaptive behavior will vary by type of disability and will be predicted by the cohesiveness of the family and by the adolescent-sibling relationship.*

This hypothesis was not substantiated. Adolescents' cognitive skills were highly related to their adaptive behavior. Overall adaptive behavior did not vary by type of disability, and neither family cohesion nor sibling relationship predicted adaptive behavior. Subdomains of adaptive behavior (e.g., daily living skills and communication skills) did differ by type of disability, however.

Hypothesis 2. *Behavior problems displayed by adolescents will vary by type of disability. Adolescents whose families experience more negative life events will display higher levels of behavior problems. Maternal problem-focused coping will moderate the relation between negative life events and behavior problems.*

This hypothesis was partially supported. In the final models neither externalizing nor internalizing behavior problems varied by type of disability. Adolescents had higher levels of internalizing (but not externalizing) behavior problems in families with higher levels of negative life events.

Hypothesis 3. Peer connectedness during adolescence will be predicted by adolescents' type of disability, gender, and the extent of behavior problems.

This hypothesis was partially supported. Neither gender nor type of disability predicted peer connectedness. Adolescents with more internalizing (but not externalizing) behavior problems had lower levels of connectedness to peers.

Hypothesis 4: Children with developmental disabilities who demonstrated higher levels of mastery motivation in early childhood will display a greater sense of autonomy during adolescence. The relation between early mastery motivation and later autonomy will be mediated by maternal parent-related stress.

This hypothesis was partially supported. Children with higher levels of mastery motivation during early childhood displayed higher levels of autonomy in adolescence. Maternal parent-related stress did not add significant variance in predicting adolescent autonomy.

Hypothesis 5. Positive maternal and paternal relationships with their adolescent with disabilities will be predicted by the main effects of parental acceptance and family cohesion and the moderating effect of the sibling relationship.

This hypothesis was partially supported. The parent-adolescent relationship was more positive for both mothers and fathers in more cohesive families. The mother-adolescent relationship was positive in families where a positive adolescent-sibling relationship was also present. The father-adolescent relationship was more positive in dyads where the father was more accepting of the adolescent with disabilities.

Hypothesis 6. Fathers, in comparison to mothers, will have greater parent-related stress. Gender of the child will interact with parent gender, and fathers of sons will have the highest level of parent-related stress. Helpful social support networks (for mothers) and the use of problem-focused coping (for fathers) will predict lower levels of parent-related stress.

This hypothesis was partially supported. Although mothers and fathers did not differ significantly in their parent-related stress, satisfaction with social support and problem-focused coping predicted less stress in both mothers and fathers.

Hypothesis 7: Parental satisfaction with health care for their adolescent with disabilities will be inversely related to the adolescent's severity of cognitive impairment and severity of health care needs. Low levels of autonomous behavior will be encouraged by the providers and exhibited by the adolescents.

This hypothesis was not substantiated. Parent satisfaction with health care services did not relate to the adolescent's cognitive skills or severity of health care needs but did relate to the type of disability (trend level). Parents of adolescents with motor impairment were least satisfied with the health care services for their adolescent. Health care providers encouraged autonomy in about one fifth of the adolescents.

Recommendations:

Several implications emerge from this work. First, the importance of young children's mastery motivation as a predictor of later autonomy suggests that ways of promoting this domain of children's behavior be more consistently considered in EI programming and services. In prior analyses we also found that early mastery motivation is an important predictor of growth in children's adaptive and cognitive skills (Hauser-Cram et al., 2001). The current analyses extend the prior work into the domain of adolescent autonomy. This domain is a critical one for all adolescents but especially for those with disabilities as it is an indicator of adult self-determination (Wehmeyer & Schwartz, 1997). The findings from EICS suggest that EI service providers should work with children with disabilities and their families to find ways of initiating more positive developmental trajectories by encouraging young children's attempts at mastering a variety of challenging tasks and activities.

Second, our findings suggest that service providers (such as health care workers, teachers and vocational counselors) be alert to the events that are occurring in an adolescent's family. Since we found that negative life events in the family relate to adolescent's behavior problems, adolescents with disabilities may need additional support and strategies for positive development during times of family crisis. This may be particularly important for those adolescents who exhibit internalizing behavior problems as they tend to be less connected to peers and thus lack the peer support typical of other adolescents.

Similarly, teachers and counselors who come into contact on a regular basis with adolescents with disabilities need to be aware of the teen's family environment given its importance in predicting parent well-being. Although school services are more child-focused and less family-oriented, teachers or counselors who become aware of potential difficulties in the adolescent's family (i.e., through parent communication about school issues or through the IEP process) should be knowledgeable of agencies that provide services to families. Mechanisms for integrating the provision of health, education, and social services remains a critical policy challenge.

Third, our data indicate that parents of children with motor impairment are less satisfied than other parents with the health care services their adolescent receives. This finding suggests that physicians and other health care service providers work to understand the areas in which the health care system can better serve adolescents with motor impairments. Such adolescents may have a high level of needs because of the

adaptive equipment they require and the additional therapies in which they should participate.

Publications:

EARLY INTERVENTION COLLABORATIVE STUDY

PUBLICATIONS

Monographs

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

Shonkoff, J. P., Hauser-Cram, P., Krauss, M. W., & Upshur, C. C. (1992). Development of infants with disabilities and their families: Implications for theory and service delivery. *Monographs of the Society for Research in Child Development, 57* (6, Serial No. 230).

Journal Articles

Warfield, M. E. (submitted). *Family and work predictors of maternal and paternal parenting role stress among two-earner families of children with disabilities.*

Warfield, M. E. (2001). Employment, parenting and well-being among mothers of children with disabilities. *Mental Retardation, 39*, 297-309.

Warfield, M. E., Hauser-Cram, P., Krauss, M. W., Shonkoff, J. P., & Upshur, C. (2000). The effect of early intervention services on maternal well-being. *Journal of Early Education and Development, 11*, 499-517.

Hauser-Cram, P., Warfield, M. E., Krauss, M. W., Shonkoff, J. P., Upshur, C. C., & Sayer, A. (1999). Family influences on adaptive behavior in young children with Down syndrome. *Child Development, 70*, 979-989.

Warfield, M. E., Krauss, M. W., Hauser-Cram, P., Upshur, C. C., & Shonkoff, J. P. (1999). Adaptation during early childhood among mothers of children with disabilities. *Developmental and Behavioral Pediatrics, 20*, 9-16.

Hauser-Cram, P. (1998). I think I can, I think I can: Understanding and encouraging mastery motivation in young children. *Young Children, 53*, 67-71.

Bronson, M.B., Hauser-Cram, P., & Warfield, M. E. (1997). Classrooms matter: Relations between the classroom environment and the social and mastery behavior of five-year-old children with disabilities. *Journal of Applied Developmental Psychology, 18*, 331-348.

Hauser-Cram, P., Krauss, M. W., Warfield, M. E., & Steele, A. (1997). The congruence and predictive power of mothers' and teachers' ratings of mastery motivation in children with mental retardation. *Mental Retardation, 35*, 355-363.

Hauser-Cram, P. (1996). Mastery motivation in toddlers with developmental disabilities. *Child Development, 67*, 236-248.

Warfield, M.E., & Hauser-Cram, P. (1996). Child care needs, arrangements, and satisfaction of mothers of children with developmental disabilities. *Mental Retardation, 34*, 294-302.

Bronson, M.B., Hauser-Cram, P., & Warfield, M.E. (1995). Classroom behaviors of preschool children with and without developmental disabilities. *Journal of Applied Developmental Psychology, 16*, 371-390.

Warfield, M.E. (1995). The cost-effectiveness of home visiting versus group services in early intervention. *Journal of Early Intervention, 19*, 130-148.

Warfield, M. E. (1994). A cost-effectiveness analysis of early intervention services in Massachusetts: Implications for policy. *Educational Evaluation and Policy Analysis, 16*, 87-99.

Krauss, M. W., Upshur, C., Shonkoff, J P., & Hauser-Cram, P. (1993). The impact of parent groups on mothers of infants with disabilities. *Journal of Early Intervention, 17*, 8-20.

Hauser-Cram, P., Bronson, M., & Upshur, C. (1993). The effects of the classroom environment on the social and mastery behaviors of preschool children with disabilities. *Early Childhood Research Quarterly, 8*, 479-497.

Krauss, M. W. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. *American Journal on Mental Retardation, 97*, 393-404.

Erickson, M. (1992). An analysis of early intervention expenditures in Massachusetts. *American Journal on Mental Retardation, 96*, 617-629.

Hauser-Cram, P., & Krauss, M. W. (1991). Measuring change in children and families. *Journal of Early Intervention, 15*, 288-297.

Upshur, C. (1991). Mothers' and fathers' ratings of the benefits of early intervention services. *Journal of Early Intervention, 15*, 345-357.

Krauss, M. W. (1990). New precedent in family policy: Individualized family service plan. *Exceptional Children, 56*, 388-395.

Erickson, M., & Upshur, C. (1989). Caretaking burden and social support: A comparison of mothers and infants with and without disabilities. *American Journal on Mental Retardation, 94*, 250-258.

Shonkoff, J. P., Hauser-Cram, P., Krauss, M. W., & Upshur, C. (1988). Early intervention efficacy research. What we have learned and where do we go from here? *Topics in Early Childhood Special Education, 8*, 81-93.

Shonkoff, J. P., & Hauser-Cram, P. (1987). Early intervention for disabled infants and their families: A quantitative analysis. *Pediatrics, 80*, 650-658.

Shonkoff, J.P. (1983). The limitations of normative assessments of high-risk infants. *Topics in Early Childhood Special Education, 3*(1). 29-43

Book Chapters

Warfield, M. E., & Hauser-Cram, P. (in press). Monitoring and evaluation in the system of early intervention programs. In M. J. Guralnick (Ed.), *A developmental systems approach to early intervention: National and international perspectives*. Baltimore, MD: Paul H. Brookes.

Hauser-Cram, P., & Kersh, J. E. (in press). Young children with developmental disabilities and their families: Needs, policies, and services. In K. M. Thies and J. F. Travers (Eds.), *Handbook of human development for health care professionals*. Thorofare, NJ: Slack.

Hauser-Cram, P., & Krauss, M.W. (in press). Adolescents with developmental disabilities and their parents. In R.M. Lerner & L. Steinberg (Eds), *Handbook of adolescent psychology*. New York: Wiley.

Hauser-Cram, P., & Howell, A. (2003). The development of young children with disabilities and their families: Implications for policies and programs. In R. M. Lerner, F. Jacobs, & D. Wertlieb (Eds.), *Handbook of applied developmental science, Vol. 1* (pp. 259-279). Thousand Oaks, CA: Sage.

Hauser-Cram, P., & Howell, A. (2003). Disabilities and development. In R. M. Lerner, M. A. Easterbrooks, & J. Mistry (Eds.), *Handbook of psychology: Vol. 6. Developmental psychology* (pp. 513-533). New York: Wiley.

Hauser-Cram, P., & Howell, A. (2001). Down syndrome. In R. M. Lerner & J. V. Lerner (Eds.) *Today's teenagers: Adolescence in America*. Denver, CO: ABC-CLIO.

Hauser-Cram, P., & Steele, A. (2001). Parenting a child with mental retardation. In L. Balter (Ed.), *Parenthood in America*. Denver, CO: ABC-CLIO.

Hauser-Cram, P., Upshur, C. C., Warfield, M. E., & Weisner, T. (2000). An expanded view of program evaluation in early childhood intervention. In J. P. Shonkoff & S. J. Meisels (Eds.) *Handbook of early childhood intervention*, 2nd edition (pp. 487-509). New York: Cambridge University Press.

Krauss, M. W. (2000). Family assessment within early intervention programs. In J. P. Shonkoff & S. J. Meisels (Eds.) *Handbook of early childhood intervention*, 2nd edition (pp. 290-308). New York: Cambridge University Press.

Shonkoff, J. P., & Marshall, P. C. (2000). The biology of developmental vulnerability. In J. P. Shonkoff & S. J. Meisels (Eds.) *Handbook of early childhood intervention*, 2nd edition (pp. 35-53). New York: Cambridge University Press.

Lerner, R. M., Hauser-Cram, P., & Miller, E. C. (1998). Assumptions and features of longitudinal designs: Implications for early childhood education. In B. Spodek, O. N. Saracho, & A. D. Pelligrini (Eds.), *Yearbook in early childhood education* (Vol. 8) (pp. 113-138). New York: Teachers College Press.

Hauser-Cram, P., Warfield, M. E., & Krauss, M. W. (1997). An examination of parent support groups: A range of purposes, theories, and effects. In W. R. Freudenburg & T. I. K. Youn (Eds.), *Research in social problems and public policy*, Vol. 6. (pp. 99-124). Greenwich, CT: JAI Press.

Krauss, M.W. (1997). The focus on families: Two generations of research in early intervention. In M. J. Guralnick (Ed.), *The effectiveness of early intervention: Directions for second generation research* (pp. 611-624). Baltimore, MD: Paul Brookes.

Hauser-Cram, P. & Shonkoff, J. (1995). Mastery motivation: Implications for intervention. In R. H. MacTurk & G. A. Morgan (Eds.), *Mastery motivation: Origins, conceptualizations, and applications* (pp. 257-272). New Jersey: Ablex.

Hauser-Cram, P. (1993). Mastery motivation in three-year-old children with Down syndrome. In D. Messer (Ed.), *Mastery motivation: Children's investigation, persistence, and development* (pp. 230-250). London: Routledge.

Hauser-Cram, P. (1993). Parent and teacher perceptions of young children's master motivation. Assessment and review of research. *Mastery motivation in early childhood: Development measurement and social processes* (pp. 109-131). London: Routledge.

Shonkoff, J. (1993). Developmental vulnerability: New challenges for research and service delivery. In N. Anastasiow & S. Harel (Eds.), *At-risk infants: Interventions, families, and research* (pp. 47-54). Baltimore: Paul H. Brookes.

Krauss, M. W. & Hauser-Cram, P. (1992). Policy and program developments for infants and toddlers with disabilities. In L. Rowitz (Ed.), *Mental retardation in the year 2000* (pp. 184-196). New York: Springer-Verlag.

Hauser-Cram, P. (1990). Designing meaningful evaluations of early intervention services. In S. J. Meisels & J. P. Shonkoff (Eds.) *Handbook of early childhood intervention* (pp. 583-602). New York: Cambridge University Press.

Krauss, M. W. & Jacobs, F. (1990). Family assessment: Purposes and techniques. In S. J. Meisels & J. P. Shonkoff (Eds.), *Handbook of early childhood intervention* (pp. 303-325). New York: Cambridge University Press.

Shonkoff, J. P. & Meisels, S. J. (1990). Early childhood intervention: The evolution of a concept. In S. J. Meisels & J. P. Shonkoff (Eds.), *Handbook of early childhood intervention* (pp. 3-32). New York: Cambridge University Press.

Upshur, C. C. (1990). Early intervention as preventive intervention. In S. J. Meisels & J. P. Shonkoff (Eds.), *Handbook of early childhood intervention* (pp. 633-650). New York: Cambridge University Press.

Hauser-Cram, P. (1988). The possibilities and limitations of meta-analysis in understanding family program impact. In H. Weiss & F. Jacobs (Eds.), *Evaluating Family programs* (pp. 445-460). New York: Aldine.

Hauser-Cram, P., & Shonkoff, J. (1988). Rethinking the assessment of child focused outcomes. In H. Weiss, & F. Jacobs (Eds.), *Evaluating family programs* (pp. 73-94). New York: Aldine.

Krauss, M. W. (1988). Measures of stress and coping in families. In H. Weiss & F. Jacobs (Eds.), *Evaluating family programs* (pp. 177-194). New York: Aldine.

Upshur, C. C. (1988). Measuring parent outcomes in family program evaluation. In H. Weiss & F. Jacobs (Eds.), *Evaluating family programs* (pp. 131-152). New York: Aldine.

I. INTRODUCTION

Statement of the Research Problem and Specific Aims

Since 1985, the Early Intervention Collaborative Study (EICS) has investigated the development of over 150 children identified with early developmental delays or disabilities, and the adaptation of their families to the challenges of parenting a child with developmental disabilities. We have also investigated the types, intensity and effects of therapeutic, social, health, and educational services received by children and their families. The current phase of this longitudinal study was designed to investigate both the health and development of these children during mid adolescence and the challenges faced by their parents.

This phase of EICS had three primary aims: First, with respect to the adolescents, the project was designed to investigate two developmental issues that are cardinal challenges of this life phase: social connectedness to peers and the emergence of personal autonomy. Second, in terms of the family unit, the adaptation of both mothers and fathers is considered central to adolescent health and development, and thus this investigation extended our focus on parent well-being into the adolescent years. Third, given the range of health care needs of adolescents with developmental disabilities, we examined parents' satisfaction with the health care delivery system for this sample of adolescents with special health care needs.

II. REVIEW OF THE LITERATURE

Developmental Tasks Confronted by Adolescents with Disabilities

Adolescence is a time of transition, transformation, and realignment for the adolescents themselves, their parents, and their siblings. Among typically developing adolescents, becoming socially competent adults engenders several important tasks. One of these tasks is individuation, defined as the disengagement from emotional dependence on adults and the development of a sense of self as a separate person (Blos, 1979) while maintaining connections to family and others (Grotevant & Cooper, 1986). The development of positive peer relations is a key aspect of this process. Through relationships with others, the adolescent learns about himself or herself, develops negotiation skills, and participates in egalitarian relationships that offer support in times of stress (Hartup, 1996).

The developmental tasks of autonomy, relatedness, and competence (Connell & Wellborn, 1991) present unique, but virtually unstudied, challenges to adolescents with disabilities because of their often compromised capacity to perform at a level consistent with their chronological age coupled with restricted opportunities provided for exercising independence (Hauser-Cram & Krauss, 2003; Turnbull & Turnbull, 1985). Nevertheless, the development of a sense of personal agency, or self-determination, may be critical for

adolescents with disabilities to support emotional well-being and determine future opportunities. For example, Wehmeyer and Schwartz (1997) reported that adolescents with developmental disabilities who had higher levels of self-determination had more positive adult outcomes (e.g., rate of employment). Overall, however, little is known about the degree to which adolescents with disabilities develop a sense of personal agency, the individual, familial, or social factors that enhance or impede varying levels of development, or the consequences in adulthood associated with marked differences in personal agency.

It is likely that, as for typically developing adolescents, relationships with parents are a key factor in the development of personal agency (Grotevant & Cooper, 1986). In a study of 29 mildly retarded adults living independently, Winik, Zetlin, and Kaufman (1985) found that those with the greatest independence and self-esteem had parents who promoted growth and autonomy. As discussed later, relationships with mothers and fathers differ substantially in their degree of support for adolescent independence and agency (Collins & Russell, 1991; Youniss & Ketterlinus, 1987), and such distinctions are important to investigate in the development of adolescents with disabilities.

A second key task in the development of social competence—constructing a supportive peer network—is also a neglected area of research on adolescents with disabilities. Studies have noted high rates of social isolation for adolescents with mental retardation and other developmental disabilities (Anderson, Clark, & Spain, 1982; Richardson, Katz, & Koller, 1993) and especially those living with their parents (Krauss, Seltzer, & Goodman, 1992). Indeed, deficits in social skills are the major factor associated with the termination of employees with mental retardation (Greenspan & Schoultz, 1981). Studies of high school students with learning handicaps indicate that these students experience high rates of peer rejection (Zetlin & Turner, 1985), and have fewer, less stable, and more conflict-ridden friendships (Zetlin & Murtaugh, 1986). Lehmann and Roberto (1996) reported that mothers of adolescents with disabilities expressed great concern about the likelihood that their son or daughter is lonely.

One cause, or result, of social isolation amongst adolescents with disabilities may be the increasing level of behavior problems exhibited by this group. For example, Zetlin and Turner (1985) noted at least 64% of their sample had behavior problems, many of which had not been present before the adolescent period. Adolescents with behavior problems have fewer opportunities for positive peer relationships and thus have less opportunity to develop negotiation skills and receive emotional support from peers. They may also produce greater burden on parents, as has been found for those adults with mental retardation who exhibit behavior problems (Seltzer, Krauss, Choi, & Hong, 1996).

In summary, there is a critical need to explore the extent to which some adolescents with disabilities demonstrate vulnerabilities as manifest through poor social networks, emerging behavior problems, and lack of independence in the management of day-to-day life tasks. Other adolescents demonstrate resilience and social competence through the development of a sense of agency, social or peer networks, and behavioral controls. We hypothesize that the development of adolescents with disabilities also

occurs within a deeply embedded web of relationships, including the primary context of the family, and the secondary contexts of various service systems, including schools and health care.

Challenges for Families of Adolescents with Disabilities

As children approach adolescence, parents must adapt to their children's changing capacities and needs and support their emerging independence and autonomy (Collins, 1990; Silverberg, 1996). Parents also need to relax the patterns of dependency and control that typify earlier stages in the family, and foster an emotional climate within the family that allows adolescents to express their own views within a context of mutual respect (Grotevant & Cooper, 1983; Harper & Lund, 1990).

For parents of children with disabilities, adolescence brings a unique set of challenges. McCallion and Toseland (1993) note that these families contend with five specific issues: ongoing emotional strains of parenting a child with a disability, potential marital discord, difficulty in negotiating developmental transitions, unresponsive service systems, and concerns about the future residential, vocational, and social lives of their adolescents with disabilities. Seltzer et al. (1996) note an additional challenge, namely that families are often negotiating two life cycles—the normative family cycle associated with their typically developing children and a modified life cycle associated with their child's disability for whom dependence needs may increase rather than decrease, during adolescence.

There is a paucity of research examining the effects on families of the transition into the teenage years of those with disabilities. In contrast to families of typically developing adolescents, parents of adolescents with disabilities may well recognize that their child is not making a transition into a new level of personal independence, but rather is likely to experience a prolonged period of dependency on the family that may well last into the adult years (Essex, Seltzer, & Krauss, 1997; Seltzer & Krauss, 1994). Given the sustained dependency of the child with disabilities and the consequent parental stress, identifying predictors of well-being for parents represents a major public health concern. Understanding the internal and external resources that support and enhance parental well-being can assist in helping parents prepare for the long stretch of parenting they may face.

Although the quality of the parent-child relationship during adolescence may be predicted by earlier experiences, a major challenge to the relationship is the management of parental concern regarding the child's competence, judgment, and future. Most adolescents with disabilities have fewer negotiation skills and more passive coping repertoires than adolescents without disabilities (Wayment & Zetlin, 1989). Parents may be more willing to accept passive levels of autonomy, and continue a practice of protective care (Murtaugh & Zetlin, 1988). Because adolescents with disabilities, in comparison to their peers, have fewer friendships and higher levels of behavior problems (Glidden & Zetlin, 1992), parents may become more, rather than less, protective during the adolescent period. Particularly among adolescents with mild mental retardation, their

vulnerability to abuse poses considerable concern for parents, including the risks associated with sexual activity and drug and alcohol abuse (Kaminer & Jedrysek, 1987).

For parents, the restricted social lives of the adolescent with disabilities (Flynn & Saleem, 1986; Richardson et al., 1993) may prompt upsetting social comparisons to the experiences of other parents or comparisons to the circumstances of their other children. Wikler (1986) noted that the passage of significant events, such as getting a driver's license or participating in school dances and other social activities, are particularly painful to parents of children with disabilities, who confront glaring differences in the life opportunities of their children from those of typically developing adolescents. Studies also have indicated that concerns over the future weigh heavily on parents of adolescents (and adults) with mental retardation and other disabilities (Krauss & Seltzer, 1995). These adults have no entitlement to community-based services after age 22, and future residential and occupational opportunities are often limited or unknown. Siblings, too, worry about the future of their brother or sister with a disability and often hold sharply divergent views from their parents regarding the future (Krauss, Seltzer, Gordon, & Friedman, 1996; Seltzer & Krauss, 1993).

Mothers and fathers must manage personal developmental issues prominent in midlife for parents of adolescents with disabilities. Among the most noted is an increase in levels of depression and anxiety. Although levels of depression and stress are not necessarily elevated among mothers and fathers of children with disabilities during the early years (Shonkoff et al., 1992), there is evidence of a dramatic increase in parental stress during the middle childhood pre-adolescent period (Hauser-Cram, Warfield, Shonkoff, Krauss, Sayer, & Upshur, 2001). In addition, gender issues may loom larger during the adolescent period, as well, as studies have found that father-son relationships become more strained during this life phase (Nydegger & Mitteness, 1996).

III. STUDY DESIGN AND METHODS

A. Study Design

The study is a continuation of a non-experimental, longitudinal investigation of a sample of children with early-identified disabilities and their families. Children and families have participated in this study since their entry into early intervention (EI) services during the child's infant or toddler years. Findings from the early childhood phase of the study can be found in Shonkoff et al., (1992), and from the early-to-middle childhood phase in Hauser-Cram et al. (2001).

B. Participants

Participants were originally recruited from 29 community-based early intervention programs in Massachusetts and New Hampshire. Parents were asked to participate if their child had Down syndrome (and was no older than 12 months of age), motor impairment (and was no older than 24 months of age), or developmental delay of unknown etiology

(and was no older than 24 months of age). The diagnosis of children with Down syndrome was confirmed by a review of the medical records. Children with motor impairment were selected to participate if they had evidence of abnormal muscle tone (hypotonia, hypertonia, or fluctuating tone) or a coordination deficit along with delayed or deviant motor development, with or without other delays. Children with developmental delays were selected to participate if they had evidence of delays in two or more areas of development with no established diagnosis or etiology that implied a specific diagnosis at the time of entry into EI.

A total of 190 children and families were initially recruited into the study. Attrition has remained at 9-10% between data collection periods. At age 15 a total of 139 adolescents (55 % male) and families continued to participate. Some families (n= 22) chose to not participate in this phase of the study, several families have moved without forwarding addresses or other means of contact (n= 19), and some children have died (n=10). The sample at age 15 consists of 42 adolescents with Down syndrome, 53 with motor impairment, and 44 with developmental delay. Almost 70% of the adolescents live with two parents. Marital status has changed in the last 5 years in 12% of the families. On average, the parents have some education beyond high school (Mean (SD)= 14.2 (2.4) years for mothers, and 13.4 (3.7) years for fathers), although parents have a wide range of educational levels (from 8th grade to graduate school). The adolescents are predominately Euro-American (91.5 %) (1.4 % African-America, 2.9 % Hispanic/Latino, and 2.2 % Asian/other). Average family income is between \$45,000 and \$50,000. In relation to employment, 89% of fathers are employed full-time, 38.2 % of mothers are employed full-time, and 32.8% of mothers are employed part time.

C. Overview of Data Collection

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

D. Measures

The constructs and measures selected for this phase of EICS, and the relevant reliabilities are listed in Table 1 below.

Table 1. Constructs and Measures

Construct	Measure	Psychometric Properties
<i>Adolescent:</i> Social Connectedness	Self-perception Profile (Harter, 1985)	EICS alpha=.71
Autonomy	The ARC's Self-determination Scale: Autonomy (Wehmeyer, 1995)	EICS alpha=.79
Adaptive Skills	Vineland Adaptive Behavior Scales (Sparrow et al., 1987)	EICS alphas= .97 to .99
Behavior Problems	Child Behavior Checklist (Achenbach & Edelbrock, 1983)	EICS alpha= .97 (internalizing) .98 (externalizing)
Cognitive Skills	Stanford-Binet Scale (Thorndike et al., 1986)	N/R
Type of Disability	Medical Records	N/R
Health	Family Partners Survey: Health Severity Rating	N/R
Mastery Motivation	Mastery Motivation Measure (Morgan et al., 1992)	N/R
<i>Mother/Father:</i> Well-being	Parenting Stress Index (Abidin, 1983)	EICS alphas=.93 (mothers) and .94 (fathers)
Family Cohesion	FACES II: Cohesion Subscale (Olson et al., 1985)	EICS alphas= .82 (mothers) and .82 (fathers)
Problem-Focused Coping	COPEs (Carver, Scheier, & Weintraub, 1989)	EICS alphas= .85 (mothers) and .89 (fathers)
Social Support	Social Support: Satisfaction (Antonucci, 1986)	N/R
Satisfaction with Health Care Services	Family Partners Survey: Satisfaction Ratings	EICS alpha=.91
Life Events	Parenting Stress Index: Life Events Scale (Abidin, 1983)	N/R
<i>Sibling:</i> Sibling Relationship	Positive Affect Scale (Bengston & Black, 1973)	EICS alpha=.94

IV. FINDINGS

Preliminary analyses were conducted to check on distributions and conduct tests of internal reliability (reported in Table 1). Table 2 provides descriptive statistics on the set of dependent variables.

Table 2
Descriptive Statistics for Dependent Variables

Variable	Mean (Standard Deviation)	
<i>Adolescent(s):</i>		
Adaptive Behavior	52.81	(38.68)
Behavior Problems: Internalizing	53.68	(11.86)
Externalizing	49.97	(12.17)
Peer Acceptance	17.40	(4.24)
Autonomy	50.36	(8.63)
<i>Parent(s):</i>		
Mother-adolescent Relationship:	70.83	(10.71)
Father-adolescent Relationship	73.85	(9.67)
Parent-related Stress: Maternal	112.18	(25.99)
Parent-related Stress: Paternal	111.14	(23.07)
Satisfaction with Health Care for Teen	9.46	(2.01)

Next, the set of seven hypotheses were examined. Each hypothesis and the results of statistical analyses are reported below. Hypotheses 1 through 6 were analyzed using linear regression. Correlational analyses were used to analyze Hypothesis 7.

Hypothesis 1. *Controlling for cognitive skills, adolescent general adaptive behavior will vary by type of disability and will be predicted by the cohesiveness of the family and by the adolescent-sibling relationship.*

Table 3
Linear Regression Analysis Summary for Predicting Adolescent Adaptive Behavior

Variable	<u>B</u>	<u>SEB</u>	<u>B</u>	Total R ²
Cognitive skills	.67	.16	.492***	28.9
Type of disability				
Down syndrome	-8.61	10.31	-.097	
Motor impaired	15.83	10.64	.181	
Family Cohesion	-.52	.57	-.101	
Sibling Relationship	-.43	.28	-.170	

*** $p < .001$

This hypothesis was not substantiated. As indicated in Table 3, adolescents' cognitive skills were strongly associated with general adaptive behavior. Overall adaptive behavior did not vary by type of disability, and neither family cohesion nor sibling relationship predicted adaptive behavior. Additional analyses of type of disability differences for subscales of adaptive behavior indicated that daily living skills ($F=8.13$, $p<.001$) and communication skills ($F=6.81$, $p <.01$) varied by type of disability. Adolescents with Down syndrome displayed the lowest skills in each of these domains.

Hypothesis 2. *Behavior problems displayed by adolescents will vary by type of disability. Adolescents whose families experience more negative life events will display higher levels of behavior problems. Maternal problem-focused coping will moderate the relation between negative life events and behavior problems.*

Table 4
Linear Regression Analysis Summary for Predicting Internalizing Behavior Problems

Variable	B	SEB	<i>B</i>	Total R ²
Down syndrome (DS)	-5.16	8.23	-.21	13.1
Negative Life Events	1.89	.57	.31**	
Problem-Focused Coping (PFC)	.03	.22	.02	
DS X PFC	.06	.35	.06	

** p < .01

Table 5
Linear Regression Analysis Summary for Predicting Externalizing Behavior Problems

Variable	B	SEB	<i>B</i>	Total R ²
Down syndrome (DS)	-14.37	9.17	-.54	3.4
Negative Life Events	0.50	.64	.07	
Problem-Focused Coping (PFC)	-.38	.24	-.19	
DS X PFC	.65	.38	.61	

As can be seen in Tables 4 and 5, the hypothesis was partially supported in relation to internalizing behavior problems. Although preliminary analysis using ANOVA indicated that adolescents with Down syndrome had lower levels of internalizing behavior problems ($F= 3.69, p<.05$), differences by type of disability (Down syndrome vs. other) were not significant in the final model. Negative life events was a significant predictor of internalizing, but not externalizing, behavior problems.

Hypothesis 3. *Peer connectedness during adolescence will be predicted by adolescents' type of disability, gender, and the extent of behavior problems.*

Table 6
Linear Regression Analysis Summary for Predicting Adolescent Peer Connectedness

Variable	<u>B</u>	<u>SEB</u>	<u>B</u>	Total R ²
Type of disability				9.5
Down syndrome	.745	1.15	.080	
Motor impaired	-.796	1.06	-.088	
Gender: Male	-.965	.91	-.112	
Behavior problems (I)	-.008	.04	-.226*	

* $p <.05$

Table 7
Linear Regression Analysis Summary for Predicting Adolescent Peer Connectedness

Variable	<u>B</u>	<u>SEB</u>	<u>B</u>	Total R ²
Type of disability				5.4
Down syndrome	1.46	1.11	.157	
Motor impaired	-1.01	1.05	-.112	
Gender: Male	-1.16	.92	-.136	
Behavior problems (E)	-.001	.04	.034	

* $p <.05$

As Tables 6 and 7 indicate neither type of disability nor gender predicted the peer connectedness of adolescents with disabilities. Adolescents with internalizing (but not externalizing) behavior problems had lower levels of connectedness to peers.

Hypothesis 4: *Children with developmental disabilities who demonstrated higher levels of mastery motivation in early childhood will display a greater sense of autonomy during adolescence. The relation between early mastery motivation and later autonomy will be mediated by maternal parent-related stress.*

Table 8
Linear Regression Analysis Summary for Predicting Adolescent Autonomy

Variable	<u>B</u>	<u>SEB</u>	<u>B</u>	Total R ²
Mastery Motivation	.06	.03	.24*	6.8
Maternal Parent-related Stress	-.03	.03	-.10	

* $p < .05$

As seen in Table 8, early childhood mastery motivation (measured as persistence in completing a puzzle-type task) added significant variance in predicting adolescent autonomy 12 years later. Maternal parent-related stress did not add significant additional variance in predicting adolescent autonomy.

Hypothesis 5. *Positive maternal and paternal relationships with their adolescent with disabilities will be predicted by the main effects of parental acceptance and family cohesion and the moderating effect of the sibling relationship.*

Table 9
Linear Regression Analysis Summary for Predicting Maternal-Adolescent Relationship

Variable	B	SEB	<i>B</i>	Total R ²
Parental Acceptance	-.29	.20	-.15	45.4
Family Cohesion (FC)	.44	.15	.32**	
Sibling Relationship (SR)	.26	.07	.38**	
FC X SR	.01	.01	.11	

** $p < .01$

Table 10
Linear Regression Analysis Summary for Predicting Paternal-Adolescent Relationship

Variable	B	SEB	<i>B</i>	Total R ²
Parental Acceptance	-.68	.26	-.33*	33.6
Family Cohesion (FC)	.56	.17	.42**	
Sibling Relationship (SR)	-.00	.08	-.00	
FC X SR	-.02	.02	-.12	

* $p < .05$; ** $p < .01$

This hypothesis was partially supported. As can be seen in Tables 8 and 9, the patterns of predictors for mother-adolescent and father-adolescent relationships are somewhat different. Adolescents from families that are more cohesive and in which the adolescent-sibling relationship is positive, are more likely to have positive relationships with their mothers. Adolescents who are more accepted by their fathers and who have cohesive families are more likely to have more positive relationships with their fathers.

Hypothesis 6. *Fathers, in comparison to mothers, will have greater parent-related stress. Gender of the child will interact with parent gender, and fathers of sons will have the highest level of parent-related stress. Helpful social support networks (for mothers) and the use of problem-focused coping (for fathers) will predict lower levels of parent-related stress.*

Table 11
Linear Regression Analysis Summary for Predicting Maternal Parent-related Stress

Variable	B	SEB	<i>B</i>	Total R ²
Child Gender: Male	-3.06	4.76	-.06	16.5
Satisfaction with Support	-7.49	3.46	-.19*	
Problem-Focused Coping	-1.49	.39	-.34***	

* p < .05; *** p < .001

Table 12
Linear Regression Analysis Summary for Predicting Paternal Parent-related Stress

Variable	B	SEB	<i>B</i>	Total R ²
Child Gender: Male	-3.36	4.38	-.08	30.6
Satisfaction with Support	-13.74	3.47	-.41***	
Problem-Focused Coping	-.99	.32	-.32**	

** p < .01; *** p < .001

This hypothesis is partially supported. Initial analyses indicated that maternal and paternal parent-related stress did not differ significantly (paired $t = .53$, $p > .05$) and were significantly correlated ($r = .38$, $p < .001$). The analyses in Tables 10 and 11 indicate that child gender was not related to parenting stress for either mothers or fathers. However, for both mothers and fathers, satisfaction with social support and the use of problem-focused coping predict lower levels of parent-related stress.

Hypothesis 7: *Parental satisfaction with health care for their adolescent with disabilities will be inversely related to the adolescent's severity of cognitive impairment and severity of health care needs. Low levels of autonomous behavior will be encouraged by the providers and exhibited by the adolescents.*

Table 13

Intercorrelations for Adolescent Cognitive Skills, Extent of Adolescent Health Care Needs and Parent Satisfaction with Health Care Services

Measure	1	2	3
1. Cognitive Skills	--		
2. Health Care Needs	-.431***	--	
3. Parent Satisfaction	.045	-.083	

*** $p < .001$

As Table 13 indicates, children with lower cognitive skills tend to have greater health care needs. However, parent satisfaction with the health care services is unrelated to adolescent cognitive skills or health care needs. Therefore, the hypothesis was not supported. In relation to the encouragement of autonomy, 21.3% of parents reported that their adolescent's physician requested to meet with the adolescent alone, and 17.3% of adolescents did so.

Additional analyses were conducted to determine if parents of adolescents in the three disability groups varied in satisfaction with health care. Parents' of adolescents with motor impairment had the lowest health care satisfaction ratings, a difference that approached significance ($F = 2.92, p = .061$).

V. DISCUSSION OF FINDINGS

A. Conclusions

The pattern of findings from these analyses relate to three general themes. First, children are agents of their own development (Brandtstadter, 1998). Adolescents with disabilities who exhibit internalizing behavior problems, are less connected to their peers. These adolescents are more withdrawn and less likely to reach out to initiate peer interaction. Therefore, adolescents' behaviors are potentially preventing positive peer

relationships which are critical to this stage of development (Hartup, 1996). Child agency also has positive implications, however. Our analyses indicate that children who display greater mastery motivation (i.e., persistence in solving a challenging problem) during early childhood develop into adolescents who show greater levels of autonomy. This finding suggests that early signs of perseverance may generate a positive growth trajectory for children with disabilities.

Second, as we have found in early phases of the life cycle of the families in our study (Hauser-Cram et al., 2001), the family environment is a critical context in which children and adolescents develop. The analyses conducted during this phase of EICS indicate that when families experience many negative life events (e.g., going into debt, parental separation or divorce, death of a family member, loss of employment), adolescents tend to exhibit greater levels of internalizing behavior problems. Such life events may be interpreted by the adolescent as a “shock to the system” and thus result in withdrawn and somaticized behaviors. The positive force of the family climate is also revealed in these analyses, however. Both mother-adolescent and father-adolescent relationships are more positive in families that function in a more cohesive fashion (i.e., families in which members enjoy activities together). Other aspects of the family environment are also critical to the promotion of mother-adolescent and father-adolescent relationships. Positive relationships between a sibling and the adolescent with disabilities is an important predictor of maternal relationship with her son or daughter with special needs. For fathers, paternal acceptance of the adolescent with disabilities is an important predictor of his relationship with his son or daughter.

A third theme that emerges from the analyses is the importance of psychological and social resources for parent well-being. In prior phases of this study, we found that mothers experience fewer increases in stress if they had strong social support networks and fathers experienced fewer increases in stress if they had strong problem-solving coping skills (Hauser-Cram et al., 2001). During this adolescent phase, it appears that both social support and problem-focus coping are related to less parent-related stress for both mothers and fathers.

B. Limitations

This study has several limitations. As with any longitudinal study, it is limited by the characteristics of the original sample. The sample is largely Euro-American, middle-income families with employed mothers and fathers. Although attrition has been limited to less than 10% between data collection periods, sample size is still somewhat limited for complex cross-sectional analyses. Nevertheless, power analyses indicate sufficient power to conduct the analyses to test the hypotheses stated in this report and to conduct future analyses we plan for the entire data set using growth modeling. Other limitations relate to the use of questionnaire data which are based on self-report of the mother, father, teen and sibling and concomitant problems concerning shared variance. We indicate when such difficulties exist in the publications that have

been developed from this data set. Finally, our models address only a portion of the complex systems in which adolescents and their families interact.

C. Policy implications

Several implications emerge from this work. First, the importance of young children's mastery motivation as a predictor of later autonomy suggests that ways of promoting this domain of children's behavior be more consistently considered in EI programming and services. In prior analyses we also found that early mastery motivation is an important predictor of growth in children's adaptive and cognitive skills (Hauser-Cram et al., 2001). The current analyses extend the prior work into the domain of adolescent autonomy. This domain is a critical one for all adolescents but especially for those with disabilities as it is an indicator of adult self-determination (Wehmeyer & Schwartz, 1997). The findings from EICS suggest that EI service providers should work with children with disabilities and their families to find ways of initiating more positive developmental trajectories by encouraging young children's attempts at mastering a variety of challenging tasks and activities.

Second, our findings suggest that service providers (such as health care workers, teachers and vocational counselors) be alert to the events that are occurring in an adolescent's family. Since we found that negative life events in the family relate to adolescent's behavior problems, adolescents with disabilities may need additional support and strategies for positive development during times of family crisis. This may be particularly important for those adolescents who exhibit internalizing behavior problems as they tend to be less connected to peers and thus lack the peer support typical of other adolescents.

Similarly, teachers and counselors who come into contact on a regular basis with adolescents with disabilities need to be aware of the teen's family environment given its importance in predicting parent well-being. Although school services are more child-focused and less family-oriented, teachers or counselors who become aware of potential difficulties in the adolescent's family (i.e., through parent communication about school issues or through the IEP process) should be knowledgeable of agencies that provide services to families. Mechanisms for integrating the provision of health, education, and social services remains a critical policy challenge.

Third, our data indicate that parents of children with motor impairment are less satisfied than other parents with the health care services their adolescent receives. This finding suggests that physicians and other health care service providers work to understand the areas in which the health care system can better serve adolescents with motor impairments. Such adolescents may have a high level of needs because of the adaptive equipment they require and the additional therapeutic services they receive.

D. Suggestions for future research

Our future work will focus on extending our investigation into analyses of the predictors of growth and change in the development of these individuals with disabilities and their families. The findings reported here suggest several important areas for future research. First, studies that focus on ways of enhancing young children's mastery motivation would produce important findings for practice in EI and other early childhood programs. Second, investigations are needed on ways of assisting adolescents with disabilities to reduce their problem behaviors and become more connected with peers.

Third, studies focused on understanding what influences the extent to which parents are accepting of their children with disabilities and on ways to increase paternal acceptance will provide insights into ways of improving fathers' relations with children with special needs. Fourth, research on ways to help individuals develop problem-focused coping skills are needed given the importance of these skills in lowering parent-related stress. Finally, studies that focus on developing a greater understanding of the health care needs of adolescents with motor impairments would be valuable.

VI. LIST OF PRODUCTS

EARLY INTERVENTION COLLABORATIVE STUDY

PUBLICATIONS AND PRESENTATIONS

Monographs

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

Shonkoff, J. P., Hauser-Cram, P., Krauss, M. W., & Upshur, C. C. (1992). Development of infants with disabilities and their families: Implications for theory and service delivery. *Monographs of the Society for Research in Child Development*, 57 (6, Serial No. 230).

Journal Articles

Warfield, M. E. (submitted). *Family and work predictors of maternal and paternal parenting role stress among two-earner families of children with disabilities.*

Warfield, M. E. (2001). Employment, parenting and well-being among mothers of children with disabilities. *Mental Retardation, 39*, 297-309.

Warfield, M. E., Hauser-Cram, P., Krauss, M. W., Shonkoff, J. P., & Upshur, C. (2000). The effect of early intervention services on maternal well-being. *Journal of Early Education and Development, 11*, 499-517.

Hauser-Cram, P., Warfield, M. E., Krauss, M. W., Shonkoff, J. P., Upshur, C. C., & Sayer, A. (1999). Family influences on adaptive behavior in young children with Down syndrome. *Child Development, 70*, 979-989.

Warfield, M. E., Krauss, M. W., Hauser-Cram, P., Upshur, C. C., & Shonkoff, J. P. (1999). Adaptation during early childhood among mothers of children with disabilities. *Developmental and Behavioral Pediatrics, 20*, 9-16.

Hauser-Cram, P. (1998). I think I can, I think I can: Understanding and encouraging mastery motivation in young children. *Young Children, 53*, 67-71.

Bronson, M.B., Hauser-Cram, P., & Warfield, M. E. (1997). Classrooms matter: Relations between the classroom environment and the social and mastery behavior of five-year-old children with disabilities. *Journal of Applied Developmental Psychology, 18*, 331-348.

Hauser-Cram, P., Krauss, M. W., Warfield, M. E., & Steele, A. (1997). The congruence and predictive power of mothers' and teachers' ratings of mastery motivation in children with mental retardation. *Mental Retardation, 35*, 355-363.

Hauser-Cram, P. (1996). Mastery motivation in toddlers with developmental disabilities. *Child Development, 67*, 236-248.

Warfield, M.E., & Hauser-Cram, P. (1996). Child care needs, arrangements, and satisfaction of mothers of children with developmental disabilities. *Mental Retardation, 34*, 294-302.

Bronson, M.B., Hauser-Cram, P., & Warfield, M.E. (1995). Classroom behaviors of preschool children with and without developmental disabilities. *Journal of Applied Developmental Psychology, 16*, 371-390.

Warfield, M.E. (1995). The cost-effectiveness of home visiting versus group services in early intervention. *Journal of Early Intervention, 19*, 130-148.

- Warfield, M. E. (1994). A cost-effectiveness analysis of early intervention services in Massachusetts: Implications for policy. *Educational Evaluation and Policy Analysis, 16*, 87-99.
- Krauss, M. W., Upshur, C., Shonkoff, J. P., & Hauser-Cram, P. (1993). The impact of parent groups on mothers of infants with disabilities. *Journal of Early Intervention, 17*, 8-20.
- Hauser-Cram, P., Bronson, M., & Upshur, C. (1993). The effects of the classroom environment on the social and mastery behaviors of preschool children with disabilities. *Early Childhood Research Quarterly, 8*, 479-497.
- Krauss, M. W. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. *American Journal on Mental Retardation, 97*, 393-404.
- Erickson, M. (1992). An analysis of early intervention expenditures in Massachusetts. *American Journal on Mental Retardation, 96*, 617-629.
- Hauser-Cram, P., & Krauss, M. W. (1991). Measuring change in children and families. *Journal of Early Intervention, 15*, 288-297.
- Upshur, C. (1991). Mothers' and fathers' ratings of the benefits of early intervention services. *Journal of Early Intervention, 15*, 345-357.
- Krauss, M. W. (1990). New precedent in family policy: Individualized family service plan. *Exceptional Children, 56*, 388-395.
- Erickson, M., & Upshur, C. (1989). Caretaking burden and social support: A comparison of mothers and infants with and without disabilities. *American Journal on Mental Retardation, 94*, 250-258.
- Shonkoff, J. P., Hauser-Cram, P., Krauss, M. W., & Upshur, C. (1988). Early intervention efficacy research. What we have learned and where do we go from here? *Topics in Early Childhood Special Education, 8*, 81-93.
- Shonkoff, J. P., & Hauser-Cram, P. (1987). Early intervention for disabled infants and their families: A quantitative analysis. *Pediatrics, 80*, 650-658.
- Shonkoff, J. P. (1983). The limitations of normative assessments of high-risk infants. *Topics in Early Childhood Special Education, 3*(1). 29-43

Book Chapters

Warfield, M. E., & Hauser-Cram, P. (in press). Monitoring and evaluation in the system of early intervention programs. In M. J. Guralnick (Ed.), *A developmental systems approach to early intervention: National and international perspectives*. Baltimore, MD: Paul H. Brookes.

Hauser-Cram, P., & Kersh, J. E. (in press). Young children with developmental disabilities and their families: Needs, policies, and services. In K. M. Thies and J. F. Travers (Eds.), *Handbook of human development for health care professionals*. Thorofare, NJ: Slack.

Hauser-Cram, P., & Krauss, M.W. (in press). Adolescents with developmental disabilities and their parents. In R.M. Lerner & L. Steinberg (Eds), *Handbook of adolescent psychology*.. New York: Wiley.

Hauser-Cram, P., & Howell, A. (2003). The development of young children with disabilities and their families: Implications for policies and programs. In R. M. Lerner, F. Jacobs, & D. Wertlieb (Eds.), *Handbook of applied developmental science, Vol. 1* (pp. 259-279). Thousand Oaks, CA: Sage.

Hauser-Cram, P., & Howell, A. (2003). Disabilities and development. In R. M. Lerner, M. A. Easterbrooks, & J. Mistry (Eds.), *Handbook of psychology: Vol. 6. Developmental psychology* (pp. 513-533). New York: Wiley.

Hauser-Cram, P., & Howell, A. (2001). Down syndrome. In R. M. Lerner & J. V. Lerner (Eds.) *Today's teenagers: Adolescence in America*. Denver, CO: ABC-CLIO.

Hauser-Cram, P., & Steele, A. (2001). Parenting a child with mental retardation. In L. Balter (Ed.), *Parenthood in America*. Denver, CO: ABC-CLIO.

Hauser-Cram, P., Upshur, C. C., Warfield, M. E., & Weisner, T. (2000). An expanded view of program evaluation in early childhood intervention. In J. P. Shonkoff & S. J. Meisels (Eds.) *Handbook of early childhood intervention*, 2nd edition (pp. 487-509). New York: Cambridge University Press.

Krauss, M. W. (2000). Family assessment within early intervention programs. In J. P. Shonkoff & S. J. Meisels (Eds.) *Handbook of early childhood intervention*, 2nd edition (pp. 290-308). New York: Cambridge University Press.

Shonkoff, J. P., & Marshall, P. C. (2000). The biology of developmental vulnerability. In J. P. Shonkoff & S. J. Meisels (Eds.) *Handbook of early childhood intervention*, 2nd edition (pp. 35-53). New York: Cambridge University Press.

Lerner, R. M., Hauser-Cram, P., & Miller, E. C. (1998). Assumptions and features of longitudinal designs: Implications for early childhood education. In B. Spodek, O. N. Saracho, & A. D. Pelligrini (Eds.), *Yearbook in early childhood education*

(Vol. 8) (pp. 113-138). New York: Teachers College Press.

Hauser-Cram, P., Warfield, M. E., & Krauss, M. W. (1997). An examination of parent support groups: A range of purposes, theories, and effects. In W. R. Freudenburg & T. I. K. Youn (Eds.), *Research in social problems and public policy*, Vol. 6. (pp. 99-124). Greenwich, CT: JAI Press.

Krauss, M.W. (1997). The focus on families: Two generations of research in early intervention. In M. J. Guralnick (Ed.), *The effectiveness of early intervention: Directions for second generation research* (pp. 611-624). Baltimore, MD: Paul Brookes.

Hauser-Cram, P. & Shonkoff, J. (1995). Mastery motivation: Implications for intervention. In R. H. MacTurk & G. A. Morgan (Eds.), *Mastery motivation: Origins, conceptualizations, and applications* (pp. 257-272). New Jersey: Ablex.

Hauser-Cram, P. (1993). Mastery motivation in three-year-old children with Down syndrome. In D. Messer (Ed.), *Mastery motivation: Children's investigation, persistence, and development* (pp. 230-250). London: Routledge.

Hauser-Cram, P. (1993). Parent and teacher perceptions of young children's master motivation. Assessment and review of research. *Mastery motivation in early childhood: Development measurement and social processes* (pp. 109-131). London: Routledge.

Shonkoff, J. (1993). Developmental vulnerability: New challenges for research and service delivery. In N. Anastasiow & S. Harel (Eds.), *At-risk infants: Interventions, families, and research* (pp. 47-54). Baltimore: Paul H. Brookes.

Krauss, M. W. & Hauser-Cram, P. (1992). Policy and program developments for infants and toddlers with disabilities. In L. Rowitz (Ed.), *Mental retardation in the year 2000* (pp. 184-196). New York: Springer-Verlag.

Hauser-Cram, P. (1990). Designing meaningful evaluations of early intervention services. In S. J. Meisels & J. P. Shonkoff (Eds.) *Handbook of early childhood intervention* (pp. 583-602). New York: Cambridge University Press.

Krauss, M. W. & Jacobs, F. (1990). Family assessment: Purposes and techniques. In S. J. Meisels & J. P. Shonkoff (Eds.), *Handbook of early childhood intervention* (pp. 303-325). New York: Cambridge University Press.

Shonkoff, J. P. & Meisels, S. J. (1990). Early childhood intervention: The evolution of a concept. In S. J. Meisels & J. P. Shonkoff (Eds.), *Handbook of early childhood Intervention* (pp. 3-32). New York: Cambridge University Press.

Upshur, C. C. (1990). Early intervention as preventive intervention. In S. J. Meisels & J. P. Shonkoff (Eds.), *Handbook of early childhood intervention* (pp. 633-650). New York: Cambridge University Press.

Hauser-Cram, P. (1988). The possibilities and limitations of meta-analysis in understanding family program impact. In H. Weiss & F. Jacobs (Eds.), *Evaluating Family programs* (pp. 445-460). New York: Aldine.

Hauser-Cram, P., & Shonkoff, J. (1988). Rethinking the assessment of child focused outcomes. In H. Weiss, & F. Jacobs (Eds.), *Evaluating family programs* (pp. 73-94). New York: Aldine.

Krauss, M. W. (1988). Measures of stress and coping in families. In H. Weiss & F. Jacobs (Eds.), *Evaluating family programs* (pp. 177-194). New York: Aldine.

Upshur, C. C. (1988). Measuring parent outcomes in family program evaluation. In H. Weiss & F. Jacobs (Eds.), *Evaluating family programs* (pp. 131-152). New York: Aldine.

Other Publications

Hauser-Cram, P. (1999). The Early Intervention Collaborative Study. *Research to Practice, 1* Bulletin of the Maternal and Child Health Bureau, Health Resources and Services Administration.

Hauser-Cram, P., Krauss, M. W., & Warfield, M. E. (1999). The Early Intervention Collaborative Study: Moving into the Adolescent Period. *Newsletter of the Boston Institute for the Development of Infants and Parent, 18*, Belmont, MA.

Shonkoff, J. (1992). Early intervention research: Asking and answering meaningful questions. *Zero-to-Three, 12*(3), 7-9.

Upshur, C., Hauser-Cram, P., Krauss, M. W., & Shonkoff, J. (1992). Transitions from early intervention to preschool: Child and family impacts. In *New directions in child and family research: Shaping Head Start in the nineties*. Administration on Children, Youth and Families & Society for Research in Child Development. 4-Mar-03

Hauser-Cram, P. (1989) Commentary: The Efficacy of Early Intervention. *Ab Initio 1* (2), 1-2.

Hauser-Cram, P., Upshur, C., Krauss, M. W., & Shonkoff, J. (1988). Implications of PL 99-457 for early intervention services for infants and toddlers with disabilities. *The Social Policy Report of the Society for Research in Child Development, 3*, 1-15.

Shonkoff, J., Hauser-Cram, P., Krauss, M. W., & Upshur, C. (1988). A community of commitment – parents, programs, and the Early Intervention Collaborative Study. *Zero-To-Three, 8*, 1-7.

Presentations (2000-2003)

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

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

Howell, A., & Warfield, M. E. (2003). *Growth in child-mother interactions among children with disabilities*. Poster presented at the biennial meeting of the Society for Research in Child Development, Tampa, April 26.

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

Hauser-Cram, P., & Warfield, M. E. (2001). *Mastery motivation as a predictor of development in children with developmental disabilities*. Gatlinburg Conference, Charleston, SC, March 5.

Hauser-Cram, P. (2001). *The Early Intervention Collaborative Study: Findings from a longitudinal investigation*. Invited address to the 8th annual conference of the Early Intervention Research Institute, Utah State, Logan, UT, March 19.

Howell, A., Hauser-Cram, P., & Warfield, M. E. (2001). *Preschool predictors of later peer acceptance and loneliness in children with disabilities*. Poster presented at the biennial meeting of the Society for Research in Child Development, Minneapolis, April 30.

Hauser-Cram, P. (2001). *The Early Intervention Collaborative Study: A longitudinal investigation of children with developmental disabilities and their parents*. Invited address to the Henry A. Murray Research Center, Radcliffe Institute for Advanced Study, Harvard University, Cambridge, MA, April 12.

Hauser-Cram, P. *Longitudinal research as a collaborative endeavor*. Invited address to Building Bridges for Child health research, policy and Practice: New Concepts and Paradigms, Women's and Children's Health policy center, Johns Hopkins University, Baltimore, MD, Oct. 16.

Dissertations

Silby, J. C. (2003). *Parental predictors of behavioral outcomes for children with developmental disabilities*. Boston College, Dept. of Counseling Psychology.

VII. LITERATURE CITED

References

- Abidin, R. R. (1983). *Parenting stress index: Manual*. Odessa, FL: Psychological Assessment Resources.
- Achenbach, T. M. & Edelbrock, C. S. (1983). *Manual for the Child Behavior Checklist and Revised Child Behavior Profile*. Burlington, VT: University Associates in Psychiatry.
- Anderson, E., Clark, L., & Spain, B. (1982). *Disability and adolescence*. London: Methuen.
- Antonucci, T.C. (1986). Measuring social support networks: Hierarchical mapping techniques. *Generations, 10*, 10-12.
- Blos, P. (1979). The second individuation process of adolescence. In P. Blos (Ed.), *The adolescent passage: Developmental issues*. New York: International University Press.
- Brandtstadter, J. (1998). Action perspectives on human development. In W. Damon (Series Ed.) & R. M. Lerner (Vol. Ed.), *Handbook of child psychology, Vol. I. Theoretical models of human development* (5th ed., pp. 807-863). New York: Wiley.
- Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology, 56*, 267-283.
- Collins, W. A., (1990). Parent-child relationships in transition to adolescence: Continuity and change in interaction, affect, and cognition. In R. Montemayor, G.R., Adams, & T. P. Gullotta (Eds.), *From childhood to adolescence: A transitional period?* (pp. 85-106). Newbury Park, CA: Sage.
- Collins, W.A., & Russell, G. (1991). Mother-child and father-child relationships in middle childhood and adolescence: A developmental analysis. *Developmental Review, 11*, 99-136.
- Connell, J. P., & Wellborn, J. G. (1991). Competence, autonomy, and relatedness: A motivational analysis of self-system processes. In M.R. Gunnar & L.A Sroufe (Eds.), *Minnesota symposium on child psychology: Vol 23. Self processes in development* (pp. 43-77). Hillsdale, NJ: Lawrence Erlbaum Associates.

- Eisen, M., Donald, C., Ware, J., & Brook, R. (1980). *Conceptualization and measurement of health for children in the Health Insurance Study*. R-2313-HEW. Santa Monica, CA: Rand.
- Essex, E.L., Seltzer, M. M., & Krauss, M. W. (1997). Residential transitions of adults with mental retardation: Predictors of waiting list use and placement. *American Journal on Mental Retardation*, *101*, 613-629.
- Flynn, M.C., & Saleem, J. K. (1986). Adults who are mentally handicapped and living with their parents: Satisfaction and perceptions regarding their lives and circumstances. *Journal of Mental Deficiency*, *30*, 379-387.
- Glidden, L.M., & Zetlin, A.G. (1992). Adolescence and community adjustment. In L. Rowitz (Ed.), *Mental retardation in the year 2000* (pp. 101-114). New York: Springer-Verlag.
- Greenspan, S., & Schoultz, B. (1981). Why mentally retarded adults lose their jobs: Social competence as a factor in work adjustments. *Applied Research in Mental Retardation*, *2*, 23-38.
- Grotevant, H.D., & Cooper, C.R. (1986). Individuation in family relationships: *Human Development*, *29*, 82-100.
- Harper, S., & Lund, D. A. (1990). Wives, husband, and daughters caring for institutionalized and noninstitutionalized dementia patients: Toward a model of caregiver burden. *International Journal of Aging and Human Development*, *30*, 241-262.
- Hartup, W.W. (1996). The company they keep: Friendships and their developmental significance. *Child Development*, *67*, 1-13.
- Hauser-Cram, P., & Krauss, M. W. (2003). Adolescents with developmental disabilities and their families. In R. M. Lerner & L. Steinberg (Eds.), *Handbook of adolescent psychology*. New York: Wiley.
- Hauser-Cram, P., Warfield, M. E., Shonkoff, J. P., & Krauss, M. W., 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).
- Kaminer, R.K., & Jedrysek, E. (1987). Risk in the lives of children and adolescents who are mentally retarded: Implications for families and professionals. In R. F. Antonak & J. A. Mulick (Eds.), *Transitions in mental retardation: Volume 3. The community imperative revisited* (pp. 72-88). Norwood, NJ: Ablex.

- Krauss, M. W., & Seltzer, M. M. (1995). Long-term caring: Family experiences over the life course. In L. Nadel & D. Rosenthal (Eds.), *Down syndrome: Living and learning in the community*. New York, NY: John Wiley.
- Krauss, M.W., Seltzer, M.M., & Goodman, S. (1992). Social support networks of adults with retardation who live at home. *American Journal on Mental Deficiency, 96*, 432-441.
- Krauss, M.W., Seltzer, M.M., Gordon, R., & Friedman, D. H., (1996). Binding ties: The roles of adults siblings of persons with mental retardation. *Mental Retardation, 34*, 83-93.
- Lehmann, J. P., & Roberto, K. A. (1996). Comparison of factors influencing mothers' perceptions about the future of their adolescent children with and without disabilities. *Mental Retardation, 34*, 27-38.
- McCallion, P., & Toseland, R. W. (1993). Empowering families of adolescents and adults with developmental disabilities. *Families in Society: The Journal of Contemporary Human Services, 74*, 579-587.
- Morgan, G. A., Busch-Rossnagel, N., Maslin-Cole, C. A., & Harmon, R. J. (1992). *Individualized assessment of mastery motivation: Manual for 15 to 36 month old children*. Unpublished document, Fordham University, Department of Psychology.
- Murtaugh, M., & Zetlin, A.G. (1988). Achievement of autonomy by nonhandicapped and mildly learning handicapped adolescents. *Journal of Youth and Adolescents, 17*, 445-460.
- Nydegger, C. N., & Mitteness, L. S. (1996). Midlife: The prime of fathers. In C. D. Ryff & M. M. Seltzer (Eds.), *The parental experiences in midlife*. Chicago: University of Chicago Press.
- Olson, D. H., Portner, J., & Lavee, Y. (1985). *FACES II*. St. Paul, MN: Family Social Science, University of Minnesota.
- Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385-401.
- Richardson, S.A., Katz, M., & Koller, H. (1993). Patterns of leisure activities in young adults with mental retardation. *American Journal on Mental Retardation, 97*, 431-442.
- Ryff, C. D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology, 57*, 1069-1081.

- Seltzer, M. M., & Krauss, M. W. (1993). Adult sibling relationship of persons with mental retardation. In Z. Stoneman & P. Berman (Eds.), *The effects of mental retardation, disability, and illness on sibling relationships* (pp. 96-116). Baltimore, MD: Paul H. Brookes.
- Seltzer, M. M., & Krauss, M. W. (1994). Aging parents with co-resident adult children: The impact of lifelong caregiving. In M. M. Seltzer, M. W. Krauss, & M. P. Janicki (Eds.), *Life course perspectives on adulthood and old age*. (pp. 3-18). Washington, DC: American Association on Mental Retardation.
- Seltzer, M. M., & Krauss, M. W., Choi, S., & Hong, J. (1996). Midlife and later-life parenting of adult children with mental retardation. In C. Ryff & M. M. Seltzer (Eds), *The parental experience at midlife*. (pp. 459-489). Chicago: The University of Chicago Press.
- Shonkoff, J. P., Hauser-Cram, P., Krauss, M., & Upshur, C. (1992). Development of infants with disabilities and their families: Implications for theory and service delivery. *Monographs of the Society for Research in Child Development*, 57(6, Serial No. 230).
- Silverberg, S.B. (1996). Parents' well-being at their children's transition to adolescence. In C. D. Ryff & M. M. Seltzer (Eds.), *The parental experience at midlife* (pp. 215-254). Chicago: University of Chicago Press.
- Spanier, G. B. (1976). Measuring dyadic adjustment: New scales for assessing the quality of marriage and similar dyads. *Journal of Marriage and the Family*, 38, 15-28.
- Sparrow, S., Balla, D., & Cicchetti, D. (1984). *Vineland Adaptive Behavior Scales. Expanded Form Manual*. Circle Pines, MN: American Guidance Service.
- Steinberg L. (1987). The impact of puberty on family relations: Effects of pubertal status and pubertal timing. *Developmental Psychology*, 23, 451-460.
- Thorndike, R., Hagen, E., & Sattler, J. (1986). *Stanford-Binet Intelligence Scale, Fourth Edition*. The Riverside Publishing Company.
- Turnbull, A.P., & Turnbull, H. R. (1985). Developing independence. *Journal of Adolescent Health Care*, 6, 108-119.
- Wayment, H.A., & Zetlin, A.G. (1989). Coping responses of mildly learning handicapped and non-handicapped adolescents. *Mental Retardation*, 27, 311-316.
- Wikler, L. (1986). Periodic stresses in families of children with mental retardation. *American Journal of Mental Deficiency*, 90, 703-706.

- Winik, L., Zetlin, A.G., & Kaufman, S. Z. (1985). Adult mildly retarded persons and their parents: The relationship between involvement and adjustment. *Applied Research in Mental Retardation*, 6, 409-419.
- Williams, G. A., & Asher, S. R. (1992). Assessment of loneliness at school among children with mild mental retardation. *American Journal on Mental Retardation*, 96, 373-385.
- Youniss, J., & Ketterlinus, R. D. (1987). Communication and connectedness in mother-and-father-adolescent relationships. *Journal of Youth and Adolescence*, 16, 265-280.
- Zetlin, A. G., & Murtaugh, M. (1988). Friendship patterns of mildly learning handicapped and nonhandicapped high school students. *American Journal on Mental Deficiency*, 89, 570-579.
- Zetlin, A.G., & Turner, J. L. (1985). Transition from adolescence to adulthood: Perspectives of mildly retarded individuals and their families. *American Journal of Mental Deficiency*, 89, 570-579.