



SECTION 4

DESCRIPTION OF FAMILIES

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Table 1 summarizes demographic information for the 40 families, and includes 42 children who originally enrolled in the study.¹ The mean age of the children at the time of their enrollment in the study was 12. These children began receiving SSI benefits between the ages of two and 16, with the average age being seven. The most common diagnosis was ADD or ADHD. Fifty-one percent of the families reported their child's ethnicity as Caucasian, with 23% being Hispanic, 17% African-American, 7% Biracial and 2% Native American.

Ninety-three percent of the primary caregivers participating in the study were female. Primary caregivers ranged in age from 21 to 61. In the majority of families (83%), the primary caregiver was the child's biological mother, with 16% being the biological father or maternal grandmother.

Thirty-five percent of the primary caregivers reported not completing high school. Fifty-two percent of the primary caregivers reported completing the twelfth grade, with 13% earning a four-year college degree. For the participants who continued through the final wave of the study ($N=25$), the majority of the primary caregivers had completed high school, a few had not graduated or earned a GED. Others had pursued education beyond high school, either in the form of college coursework or trade school. Several had two-year college, business or trade degrees or certifications. Only one had earned a four-year college degree. One mother was a certified nurses aid, while another had earned her certification as a parent support specialist in mental health.

The average SSI payment was \$445 per month and covered a range including a low of \$128 to a high of \$517. These benefits represented an average of 41% of the families' total household income, ranging from 15% to 100%. At the beginning of the study, half of the 40 participating families were no longer receiving SSI benefits, while the remaining families were either receiving benefits while appealing a denial, or had retained their benefits. This finding reflects the SSA estimates that as of November 1997, 48% of the families of children who were subjected to a re-determination continued their eligibility, while 52% were notified of an unfavorable re-determination.

Across sites, most of the families were renting an apartment or house, with five owning their own homes. Of those who were renting, a few were in HUD subsidized or other publicly assisted housing, while others were living with relatives. They had lived in their current residences for between 5 and 13 years.

Initial collective focus group demographics are provided in Table 2.

SSI percent of Families' Income for 25 Respondents	
SSI % of Income	Number of Families
0%-25%	9
26%-50%	14
51%-75%	1
76%-100%	1

¹ Two families had two children each included in the study.

Table 1

SSI Family Interview Demographics				
Demographic	Florida (N = 15)	Kansas (N = 12)	New York (N = 13)	Collective (N = 40)
Age of Children (Mean/Range)	M = 12 R = 7 to 18	M = 12 R = 7 to 19	M = 14 R = 6 to 18	M = 13 R = 6 to 19
Age Child Began Receiving Benefits (Mean/Range)	M = 6 R = 2 to 11	M = 7 R = 2 to 12	M = 6 R = 4 to 11	M = 6 R = 2 to 16
Gender of Children	13 Male 2 Female	10 Male; 3 Female (2 children participating from one family)	13 Male; 1 Female (2 children participating from one family)	36 Male; 6 Female (2 children participating from each of two families)
Ethnicity of Children	9 Caucasian 3 Hispanic 2 Biracial 1 African-American	12 Caucasian 1 Biracial	6 Hispanic 6 African-American 1 Native-American	21 Caucasian 9 Hispanic 7 African-American 3 Biracial 1 Native American
Diagnosis of Children	10 ADD/ADHD Other Dx: Bipolar, Obsessive-Compulsive Disorder, Dysthymia, Agoraphobia, Cerebral Palsy, "Emotionally Handicapped," Intermittent Explosive Disorder	7 ADHD 5 Learning Disability 2 Behavioral Disorder 2 Seizure Disorder Other Dx: Obsessive Disorder, Post Traumatic Stress Disorder, Birth Defects, Bipolar, "Emotional Problems," "Possible Mental Retardation"	6 ADD/ADHD 3 Learning Disability 3 Severe Emotional Disorder Other Dx: Mild Retardation, Explosive Disorder	25 ADD/ADHD 8 Learning Disability 5 Severe Emotional/Behavioral Disorder 2 Bipolar 2 Seizure Disorder 2 Explosive Disorder 2 Emotionally Handicapped/Problems 2 Obsessive-Compulsive Disorder Other Dx: Dysthymia, Agoraphobia, Cerebral Palsy, PTSD, Birth Defects, MR
Age of Primary Caregiver (Mean/Range)	M = 37 R = 26 to 46	M = 40 R = 31 to 55	M = 40 R = 21 to 61	M = 39 R = 21 to 61
Gender of Primary Caregiver	13 Female 2 Male	12 Female	12 Female 1 Male	37 Female 3 Male
Relationship to Child	12 Biological Mothers 2 Biological Fathers 1 Relative Custody	10 Biological Mothers 2 Maternal Grandmothers	11 Biological Mothers 1 Biological Father 1 Maternal Grandmother	33 Biological Mothers 3 Biological Fathers 3 Maternal Grandmothers 1 Relative Custody
Educational Level of Primary Caregiver Achieved	5 High School 2 AA/years of College 1 College Degree 1 GED 1 11 th Grade 1 6 th Grade 4 – Not Reported	5 High School + Vocational Training 4 High School 2 8 th Grade 1 11 th Grade	4 College Degree 4 High School 2 11 th Grade 2 9 th Grade 1 8 th Grade	5 College Degree 18 High School (4 + Vocational Training) 2 AA Degree 1 GED 4 11 th Grade 2 9 th Grade 3 8 th Grade 1 6 th Grade 4 – Not Reported
Number in Household (Mean/Range)	M = 4 R = 2 to 7	M = 4 R = 2 to 6	M = 4 R = 2 to 5	M = 4 R = 2 to 7
SSI as % of Income (Mean/Range)	M = 36% R = 17% to 100%	M = 27% R = 15% to 50%	M = 54% R = 37% to 75%	M = 39% R = 15% to 100%
Amount of SSI Received (Mean/Range)	M = \$390 R = \$200 to \$500	M = \$387 R = \$128 to \$484	M = \$514 R = \$480 to \$517	M = \$430 R = \$128 to \$517
Number No Longer Receiving Checks at Wave 1 of study	9	10	1	20
Status of Appeal at Wave 1	11 Appealed 9 Won Appeal 2 Lost 1 st Appeal 4 Not Appealing	8 Appealed 4 Won Appeal 4 Lost 1 st Appeal 4 Not Appealing	4 Appealed 2 Won Appeal 1 Waiting 1 Lost 1 st Appeal 9 Not Appealing	23 Appealed 15 Won Appeal 7 Lost 1 st Appeal 1 Waiting on Appeal 17 Not Appealing

M = Mean

R = Range

Table 2

SSI Family Focus Group Demographics				
Demographic	Florida (N = 8)	Kansas (N = 9)	New York (N = 5)	Collective (N = 22)
Age of Children (Mean/Range)	M = 12 R = 6 to 17	M = 12 R = 7 to 18	M = 11 R = 9 to 12	M = 12 R = 6 to 18
Gender of Children	4 Male 4 Female	8 Male 2 Female	3 Male 2 Female	15 Male 8 Female (2 children in one family in Kansas)
Ethnicity of Children	5 African-American 2 Caucasian 1 Hispanic	9 Caucasian 1 Biracial	2 Hispanic 2 African-American 1 West Indies	11 Caucasian 7 African-American 3 Hispanic 1 West Indies
Diagnosis of Children	ADHD Learning Disability Severe Emotional/Behavioral Disorder Seizure Disorder Mild Narcolepsy Past Sexual Abuse Past Physical Abuse	9 ADHD Learning Disabled Behavioral Disorder Seizure Disorder Bipolar	Schizophrenia Conduct Disorder Depressive Disorder Learning Disability Severe Emotional Disorder Speech Impairment	ADD/ADHD Learning Disability Severe Emotional/Behavioral Disorder Conduct Disorder Seizure Disorder Speech Impairment Mild Narcolepsy Past Sexual Abuse Past Physical Abuse Depressive Disorder
Age of Primary Caregiver (Mean/Range)	M = 45 R = 31 to 64	M = 40 R = 31 to 55	M = 37 R = 29 to 49	M = 41 R = 29 to 64
Gender of Primary Caregiver	8 Female 0 Male	9 Female 0 Male	5 Female 0 Male	22 Female 0 Male
Relationship to Child	5 Biological Mothers 2 Maternal Grandmothers 1 Adoptive Mother	8 Biological Mothers 1 Maternal Grandmother	5 Biological Mothers	18 Biological Mothers 3 Maternal Grandmothers 1 Adoptive Mother
Number Employed	3	3	3	9
Educational Level of Primary Caregiver Achieved	1 College Degree 1 AA/years of College 4 High School 1 GED 1 11 th Grade	1 AA/years of College 5 High School + Vocational Training 2 High School 1 11 th Grade	4 High School 1 6 th Grade	1 College Degree 2 AA/Years of college 5 High School + Vocational training 10 High School 1 GED 2 11 th Grade 1 6 th Grade
Number No Longer Receiving Checks at Wave 1 of study	6	9	1	16
Status of Appeal at Wave 1	8 Appealed 2 Won Appeal 6 Lost 1 st Appeal	8 Appealed 4 Won Appeal 4 Lost 1 st Appeal 1 Not Appealing	4 Appealed 1 Won Appeal 3 Lost 1 st Appeal 1 Not Appealing	20 Appealed 7 Won Appeal 13 Lost 1 st Appeal 2 Not Appealing