Appendix A

Studies Tracking the Impact of Changes to the Children’s SSI Program

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The objective of this study is to assess and describe the impact of new regulations on families and children whose serious emotional disability had previously qualified them for SSI and who have lost or may lose these benefits. The study will describe the experiences of 36 families whose children were re-evaluated to determine if they continue to qualify for SSI cash benefits under the new childhood disability regulations. Although some children in the study will still qualify, others will lose their eligibility. The study will analyze the impact of the new regulations for these families by documenting:

- socio-demographic and socio-economic profiles;
- initial experiences obtaining eligibility;
- changes faced when children lose SSI benefits;
- decisions made when children lose SSI benefits; and
- formal and informal supports available to help adjust to loss of SSI benefits.

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This study, requested by Congress in the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 will analyze extra expenses incurred by families of children receiving SSI benefits that are not covered by other federal, state or local programs. The study seeks to answer two key questions:

1. What disability-related expenses do families have for their SSI children?
2. How do federal, state and local programs affect out-of-pocket expenses that families have for their SSI children?


Social Security Administration (SSA)

Several parts of the agency are studying the impact of changes in the children's SSI program:

1. The Office of Disability is examining whether multi disciplinary assessments or particular tests change outcomes or improve adjudication of children's applications for SSI benefits. The study targets children ages 6-15 who have cognitive impairments and would be denied under SSA's current disability evaluation procedures. Up to 200 cases will be selected among children who have a diagnosis of mental retardation or borderline intellectual functioning OR have speech or language deficits. The children selected will receive a multi-disciplinary assessment at their state UAP. Six UAPs are participating: California, Iowa, Maryland, Rhode Island, Tennessee and Wisconsin.

2. Assessment of Data Sources to Evaluate Impact of Children's SSI Program Changes

Ten publicly-funded databases were assessed to determine their ability to analyze the effects of the new childhood disability definition. A Special Report, submitted to SSA in February 1998, concluded that no existing databases were large enough to identify sub-populations of children with disabilities or able to link to SSA administrative data to track trends in childhood disability and the SSI population.

Several observations in the report have particular significance for children with serious mental health problems:

- The report acknowledged that to analyze the potential implication of future SSA policy changes, it may be desirable to include children who are potentially eligible, but not currently receiving benefits for any number of reasons— the stigma; poor information about program eligibility rules; financial ineligibility; new definition
of childhood disability. Having a larger sample would be useful for the population of children with mental health problems who were previously eligible, but who no longer qualify under the new childhood disability definition.

- Only limited information is now available about what mental health services children use.

- Only one survey includes information on the time spent by the caregiver with the child. Since childhood disability imposes unusual time demands on parents, it would be very useful to have this information when evaluating proposed SSI changes as well as analyzing the impact of childhood disability on child and family well-being. The report suggests that knowing how much time a caregiver must devote to a child's needs may be important to know when designing eligibility criteria because particular disabilities may impose greater demands upon the parent.

- The surveys vary in how they report mental health information which reflects basic disagreements about how to measure mental impairments. Since the surveys only report if a health or education professional has told the family that the child has a behavioral or emotional problem, no information is available about the duration or severity of the child's impairment.

Based on the report's conclusion that there is no nationally representative database with a focus on childhood disability, SSA decided to undertake a national survey of SSI children.

3. National Survey of SSI Children

- Contractor—Mathematica Policy Research, Inc.

- Objective—develop a national representative survey of SSI children to provide information for SSA to use when evaluating the impact of current and future policy changes.

- Scope—develop the sampling methodology and survey delivery technique, design the survey instrument and pre-test the sample design and survey.

- Methodology—Among the questions the survey will be designed to answer are:
  - What is the cost of caring for a child with a disability?
  - How do families use SSI benefits?
  - What alternative sources of care are available to children who lose SSI benefits?
  - How are quality of life, utilization of medical services and school performance affected by having or losing SSI benefits?
- What is the impact on parental labor force participation among families whose children receive SSI benefits?

Possible groups of children to be included in the sample design include: SSI children whose eligibility was re-determined under new disability regulations; SSI children whose eligibility was not re-determined; and children with disabilities who do not receive SSI benefits. All efforts will be made to include appropriate representation of children affected by the changes, especially those with mental disabilities.

Mathematica will develop the sampling methodology and survey delivery technique, design the survey instrument and pre-test the sample design and survey for SSA by fall 1999. OMB clearance is required for the survey to be conducted. A second, competitively-awarded contract will conduct the survey and prepare the data files. Data collection is expected to begin in 2000.

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- Contractor—Rand Corporation

- Objective—examine the effects of new children’s SSI regulations on children with disabilities, future SSI caseloads and program costs.

- Scope—track status of re-determinations; evaluate effects of legislation on children’s SSI caseloads and program costs; provide quantitative analyses of how legislation affects economic well-being and health care utilization of children losing SSI benefits; provide qualitative analyses of how losing SSI benefits affects children with disabilities and their families.

- Methodology—qualitative and quantitative

  Study Questions
  - What are the characteristics of the children affected by the welfare legislation? What happens to their family income, living arrangements and other relevant outcomes?
  - What is the impact of the legislation on children with disabilities who were receiving SSI benefits prior to the welfare changes? How many children lose their benefits and what is the impact on program caseloads and costs?
  - How many children would have qualified for SSI but did not because of changes in the eligibility rules? What is the resulting impact on caseloads and program costs?
Quantitative Analyses
- Evaluate SSA administrative data in February, May, August and November 1998 and June 1999 to provide information about the number of pending disability reviews, continuances, cessations and cases pending appeal. Data will be tabulated to indicate different characteristics of the children in each caseload groups—e.g., sex, age, race, living arrangements, disability diagnosis and geographic location. To determine the legislation's impact, the contractor will construct econometric models to estimate what caseloads and costs would have been without the mandated changes.

- Use Survey of Income and Program Participation (SIPP) to study effects of changes on the economic well-being of families whose children lose benefits by examining outcomes such as family income, participation in other income support programs, parental labor force status and the child's living arrangement.

- Use Medicaid Statistical Information System (MSIS) to analyze effects of losing SSI cash assistance on health care utilization and expenditures; determine the extent to which children who were entitled to “grandfathering” in Medicaid were re-enrolled or lost coverage; and track the Medicaid enrollment status of age 18 cases who lose their SSI benefits.

Qualitative Analyses
- Case studies in four states (California, Connecticut, Louisiana and Michigan) in two rounds, one year apart. Visits will include interviews with regional and local SSA offices, local agencies and providers, and a random sample of families of children who previously received SSI benefits. Issues to explore include: legislation’s impact on SSA staff operations and role of local agencies providing services to families whose children lose eligibility.
  - Families will be asked to describe how their lives have changed as a result of losing SSI.
  - Did the child’s health status or ability to function change?
  - Did the child’s use of public health and mental health services change?
  - Did the child’s access to medical and health-related services change?
  - Does the child use special school services? Do they affect school performance?
  - Did the child’s access to publicly-funded care coordination through Title V, Medicaid case management or early intervention change?
  - Did the family structure or living arrangements change?
- Did changes in parent employment or working hours affect the child’s time with the parent, use of child care and access to services?
- How were SSI benefits used when the child was eligible?
- What out-of-pocket expenses does the family have for the child with disabilities?
- How has income changed since the termination of SSI benefits?
- What proportion of family income did the monthly SSI payment represent?
- Is the child/family receiving other assistance that substitutes for the lost SSI income?
- Have parental working hours changed since the SSI income was lost? Are they expected to change?

- States were selected to represent variations among regions of the country; caseload sizes; SSI participation rates; share of caseloads with children most affected by the changes (i.e. those who previously qualified through the individualized functional assessment or with a diagnosis of “maladaptive behavior”); initial continuation rates; accuracy of cessations and continuations; state policy and economic environment; parameters of state Medicaid program; and the generosity of publicly-funded social support programs. Five study sites were selected: California (Los Angeles and Fresno); Connecticut (Hartford); Louisiana (Orleans Parish); and Michigan (Wayne County which includes Detroit).
Appendix B

Glossary of Terms

Aid to Families with Dependent Children (AFDC)—provided case payments to needy children (and their caretakers) who lack support because at least one parent is dead, disabled, or continually absent from the home, or unemployed. The cash payment depended upon the family's cash income and size, as well as the state in which the family lives. In 1996, AFDC was replaced with Temporary Assistance to Needy Families (TANF). Some programs previously linked to AFDC (Medicaid, for example) continue to use AFDC eligibility standards to determine qualification for these benefits.

Categorical Exemption—exemptions from requirements awarded to Aid to Families with Dependent Children (AFDC) beneficiaries. Such exemptions were eliminated with the passage of PRWORA.

Child Care and Development Block Grant (CCDBG)—P.L. 104-193 eliminated the federal child care entitlements and block granted federal child care subsidies for low-income children. The Child Care and Development Block Grant provides federal child care funds for states for assistance to low-income families, as well as for activities to improve the overall quality and supply of child care for all families.

Child-only cases—Cases in which relative caretakers receive assistance from TANF for the children of relatives that they care for. The relative caretaker receives no cash benefits for herself.

Eligible families—must meet two criteria: (1) include a child living with his or her custodial parent or other adult caretaker relative (or a pregnant woman); and (2) be financially eligible according to the appropriate income/resource standards established by the State in its TANF plan. “Eligible families” includes those eligible for TANF assistance, as well as those who could be eligible, but for the time limit on the receipt of federally funded assistance or PRWORA’s restrictions on benefits to immigrants.
Emergency Assistance (EA)—States no longer receive funding specifically for an emergency assistance (EA) program, though they generally can use their TANF block grant dollars or state maintenance-of-effort dollars to provide the kinds of benefits that were formerly provided through EA.

Family Violence Option—The Family Violence Option permits a state to waive TANF program requirements for a victim of domestic violence if complying with the requirements would make it more difficult for the victim to escape domestic violence or would unfairly penalize the individual. Under the FVO, the State must also develop a system to screen for victims of domestic violence and refer them to appropriate counseling and supportive services.

Hardship Exemption—an exemption permitted by the PRWORA that is determined by the state. A state can exempt up to 20% of its caseload from the federal lifetime limits on receipt of TANF funds. This exemption is based on particular “hardship” circumstances as defined by the state. Stopping the time limit clock for a family recognizes that, because of the family’s current circumstances, receipt of aid during that month should not count against the family’s time limit.

IDEA Part C—Pact C established the program for infants and toddlers with disabilities as a federal grant program that assists states in operating a comprehensive statewide program of early intervention (EI) services for children ages birth through age 2 years, and their families.

Individuals with Disabilities Education Act (IDEA)—This Act is designed to provide free appropriate public education to children with disabilities. The Act sets out a detailed procedure by which children are evaluated and appropriate programs of special education are developed. Eligible children under IDEA will have one of 13 disabilities identified by IDEA. Children between the ages of 3 and 21 (or graduation from high school education, whichever occurs first) are eligible for free appropriate public education.

Individualized Education Program (IEP)—For a program to be “appropriate” under IDEA it must be based on and responsive to the child’s individualized educational needs as identified in the evaluation process. IDEA requires a written Individual Education Program (IEP) to be developed for each eligible child. The IEP identifies goals, objectives and special instruction and other related services necessary for the child to benefit from the program.

Individualized Functional Assessment (IFA)—Prior to passage of welfare reform legislation, the IFA was utilized to assess whether a child’s
mental, physical and social functioning was substantially lower than that of other children the same age. The IFA supplemented SSA’s listing of medical impairments by providing a measure of how a child’s impairments affected his or her ability to function. Since the passage of the PRWORA, children are no longer able to qualify for SSI through the IFA.

**Kinship care**—In its broadest sense, kinship care is any living arrangement in which a relative or someone else emotionally close to a child takes primary responsibility for rearing that child (Leos-Urbel, et al.)

**Maintenance of effort (MOE)**—PRWORA requires that for each fiscal year, a State must spend State funds in an amount equal to at least 80% of the amount it spent in FY 1994. But, if the State meets the minimum work participation rate requirements for all families and two-parent families, then it need expend only 75% of the amount it spent in FY 1994. Under the TANF MOE provisions, a State may expend these State MOE funds on a wide variety of services, benefits, and supports that help families become self-sufficient. A State must use all of its MOE funds to help “eligible families.”

**Medicaid**—a federal and state entitlement program to provide medical care coverage to low-income disabled, blind, and elderly persons, and families with children. States have the flexibility to design their own Medicaid packages, but they must adhere to federal minimum requirements to be awarded matching federal funds. The PRWORA changed the automatic eligibility link between Medicaid and cash assistance.

**Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA)**—P.L. 104-193. The PRWORA, which became law on August 22, 1996, ended the federal entitlement to public assistance and granted a great proportion of autonomy to states in implementing and operating their welfare assistance programs. The Act creates a single capped entitlement to states, called Temporary Assistance for Needy Families (TANF), that block grants the former programs Aid to Families with Dependent Children (AFDC), Emergency Assistance (EA), and Job Opportunities and Basic Skills (JOBS). The Act also set forth a number of important provisions related to issues such as child care, child support enforcement, teen parents, food stamps, and Supplemental Security Income (SSI).

**Ryan White CARE Act**—In 1990 Congress passed P.L. 101-381, the Ryan White CARE (Comprehensive AIDS Resources Emergency) Act, to improve the quality and availability of care for individuals and families with HIV disease who would otherwise have limited access to such care.
Sanctions—States are required to sanction individuals for noncompliance with TANF program requirements or for failure to cooperate with child support enforcement efforts. The state has the option to either reduce or terminate cash benefits for the family, and also terminate Medicaid for the adult who fails to meet the work requirement.

Second Chance Homes—Alternative, adult-supervised living arrangements for teen parents who are unable to live with a parent or guardian.

Section 1931 of the Social Security Act—Creates a new Medicaid eligibility category which allows families to qualify for Medicaid if, at a minimum, they meet AFDC standards that were in effect on July 16, 1996. Section 1931 also allows states to expand Medicaid coverage beyond these minimum federal requirements to cover more low-income, or two-parent working families. The statute requires that eligibility for Medicaid be determined separately from eligibility for TANF.

Social Services Block Grant (Title XX)—provides flexible funding to states for a variety of social services, as long as the funds are used within the parameters of five broad federal goals, which are aimed at promoting self-sufficiency.

State Children’s Health Insurance Program (SCHIP)—the Balanced Budget Act of 1997 created Title XXI of the Social Security Act, the State Children’s Health Insurance Program, and provided capped matching funds to states that want to expand health insurance to low-income children who do not qualify for Medicaid. The states have the option to expand Medicaid, create a new health insurance program, or develop a combination of the two.

Supplemental Security Income (SSI)—a federal program that provides monthly payments to people who are age 65 or older or are blind or have a disability and who have little or no resources or income. The program is administered by the Social Security Administration and financed from general funds of the U.S. Treasury.

Temporary Assistance to Needy Families (TANF)—established in 1996 as part of the Personal Responsibility and Work Opportunity Reconciliation Act (P.L. 104-193). TANF replaced the former Aid to Families with Dependent Children (AFDC), Emergency Assistance (EA) and the Job Opportunities and Basic Skills (JOBS) programs as a block grant to the states with new requirements and tighter restrictions for families seeking financial assistance. As a block grant, TANF also provides states with more flexibility in the use of these funds.
**Time Limits**—TANF provisions indicate that a beneficiary may receive federal TANF assistance for up to 60 months. States have the option to set shorter time limits on the receipt of TANF benefits.

**Title IV-A of Social Security Act**—“Block Grants to States for Temporary Assistance to Needy Families.” Funding for TANF and related programs comes from Title IV-A.

**Title IV-B of the Social Security Act**—“Child and Family Services.” This part authorizes funds to state public welfare agencies in establishing, extending, and strengthening child welfare services. Funds may be used for services to families and children without regard to their eligibility for AFDC. Subpart 2 of Title IV-B, “Promoting Safe and Stable Families”, was established in 1997 for the purpose of encouraging and enabling each state to develop and establish, or expand, and to operate a program of family preservation services, community-based family support services, time-limited family reunification services, and adoption promotion and support services. Prior to 1997, the Promoting Safe and Stable Families Act was known as the Family Preservation and Support Services Program.

**Title IV-D of the Social Security Act**—“Child Support and Establishment of Paternity.” This part is for the purpose of enforcing the support obligations owed by non-custodial parents to their children and the spouse (or former spouse) with whom such children are living, locating non-custodial parents, establishing paternity, obtaining child and spousal support, and assuring that assistance in obtaining support will be available under this part to all children for whom such assistance is requested.

**Title IV-E demonstration waiver (Child Welfare Demonstration Projects)**—provides states with an opportunity to design and test a wide range of approaches to improve and reform child welfare by waiving certain requirements of Title IV-E. The general objectives of the waivers include the development of family focused, strengths-based, community-based service delivery networks that enhance the child-rearing abilities of families, to enable them to remain safely together when possible, or to move children quickly to permanency; and development of better results for children and families.

**Title IV-E of Social Security Act**—“Federal Payments for Foster Care and Adoption Assistance.” This part provides funds to states to provide foster care, transitional independent living, and adoption assistance programs for children who otherwise would have been eligible for AFDC if still in their own homes.
Title V/ Maternal and Child Health Services Block Grant – a federal-state partnership that supports and develops community-based solutions devoted to improving the health of all mothers and children. The goals of the block grant include preventing death, disease and disability; assuring access to quality health care; and providing family-centered, community-based services for children with special health care needs.

Title XXI — see State Children's Health Insurance Program (SCHIP)

Transitional Medicaid Assistance (TMA) — As under pre-PRWORA, if a family loses Medicaid eligibility because of employment or receipt of support payments and received Medicaid in three of the preceding six months, the family is eligible for a period of extended Medicaid benefits.

Welfare-to-work — PRWORA and TANF reforms made moving people from welfare to work a primary goal of federal welfare policy. The Balanced Budget Act of 1997 furthered this goal, authorizing the U.S. Department of Labor (DOL) to award $3 billion in welfare-to-work grants to states and local communities to promote job opportunities and employment preparation for the hardest-to-employ recipients of TANF and for non-custodial parents of children on TANF.

Work Participation — States must require TANF recipients to participate in work activities (as defined by the state) when they are determined ready or within 24 months. States have the option to set a shorter time frame.