



# SECTION 1

## INTRODUCTION

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## Background

The Supplemental Security Income (SSI) program, since its inception in 1974, is intended to ensure that families have sufficient income to meet their children's basic needs. The SSI program provides cash benefits, up to \$484 per month or \$5,808 a year, for each eligible child, and also provides for Medicaid coverage. It has come to represent an important safety net for some of the most vulnerable families. With SSI, the families must not only qualify for the benefit based on financial consideration, but the child must also qualify based on a physical or mental impairment.

Before 1996, children with emotional and behavioral disorders could qualify for SSI benefits on the basis of impairments that seriously limited their ability to perform activities normal for their age. The welfare law that took effect in 1996, the Personal Responsibility and Work Opportunity Act (PRWOA), established a new and stricter definition of disability specifically for children, making it harder for children to demonstrate a disability, thus changing the way children qualify for SSI disability benefits. Under the PRWOA, an eligible child now must have "marked and severe functional limitations" from a physical or mental condition. The child's condition or combination of conditions must meet or "medically or functionally equal" a condition in the Social Security Administration's (SSA) revised listings of impairments, which no longer include "maladaptive behavior" as a measure of disability. Under PRWOA the agency no longer uses the same functional assessment to evaluate limitations, although it must consider all evidence of a child's functional limitations. Additionally, the PRWOA required the SSA to re-determine the cases of children whose eligibility might terminate because of the provisions of the law.<sup>1</sup>

More than 263,000 children of the one million children on the SSI rolls in 1996 were identified as being potentially affected by the revised criteria. In 1996, federal officials notified these families with children on the disability rolls that the new law may affect them and that their cases would be reviewed. These were children whose disability determination was based on the Individualized Functional Assessment (IFA), an important medical evaluation process, or consideration of maladaptive behaviors in the personal behavior domain. According to the SSA, while other children would also be affected (children with tuberculosis, mental retardation, development disabilities, burns, arthritis, and intracranial injuries who also qualify for SSI through IFA), the elimination of the IFA would disproportionately impact children with mental health problems.

### Children's Supplemental Security Income (SSI) Relevant Provisions in the Law

#### New Standard of Childhood Disability Eligibility Changes

- Children have to qualify for SSI under a stricter definition of disability.
- Children are no longer able to qualify through the Individualized Functional Assessment (IFA).
- Eligibility criterion (known as the medical listing of impairments) is changed to reduce the importance of "maladaptive behavior" for children with mental disorders.

#### Redetermination

- Certain children receiving SSI benefits were to be reviewed to determine if they still qualified under the new childhood disability criteria.

#### Medicaid Eligibility

- With stricter disability standards, approx. 30,000 were expected to lose Medicaid. However, under the Balanced Budget Act of 1997, children who were receiving SSI benefits, but lost their eligibility because of the new criteria, will not lose Medicaid coverage.

#### SSI Redeterminations for Young People Turning Age 18

- Review for those individuals who are eligible for SSI benefits at the time they turn 18 using the rules for determining adult eligibility.

### SSI Results Based on Data through October 31, 1998

- There were 998,280 children receiving SSI.
- 57.9% of children whose cases were reviewed were continued in the program.
- 42.1% of children had their benefits terminated (based on first level of appeal).

*The Bazelon Center for Mental Health Law*

<sup>1</sup> Provided by the Bazelon Center for Mental Health Law, 1999.

The SSA was given until August 22, 1997 to conduct the reviews, ultimately re-evaluating approximately 288,000 children to determine if they met the revised criteria. Data compiled by the SSA indicated that most of the children who ended up losing disability benefits (after one or more appeals)—78,600 of the 95,180—had “mental disorders.” This represented about 83% of all the re-determined cases that were found ineligible.

## Purpose of Study

In September 1997, the Center for Mental Health Services (SAMHSA) funded the de la Parte Florida Mental Health Institute to examine the impact of changes in the SSI policy on families with children who had been receiving SSI benefits because of a serious emotional disability and who were in jeopardy of losing those benefits. In September 1999, in order to capture the long term effects on families, the National Institute on Disability and Rehabilitation Research and the Center for Mental Health Services provided continued funding for twelve additional months of study.

The SSI Family Impact Study seeks to understand the impact, both positive and negative, of new federal regulations on families and children whose serious emotional disability had previously qualified them to receive SSI disability benefits, and for whom continuation of this benefit was in jeopardy or had already been lost. At the individual and family level, this is a study in coping, decision-making, and resilience in response to major changes in an important formal support system. At the macro level, the study has implications for federal, state and local policymakers, evaluators and the family advocacy movement.

## Organization of Report

This study is comprehensive but not exhaustive in its coverage of the impact of the changes in regulations and eligibility of SSI benefits on children with an emotional or behavioral disability and their families. It is intended to be used as a companion and supplement to the quantitative estimates of the effect of the legislation on disabled children who were on the SSI rolls prior to the legislation’s enactment.<sup>3</sup> By listening to the stories of families whose lives are impacted by policy changes outside their immediate control, and by assessing the comprehensive effects of these changes, service and support systems can offer more strategic and individualized interventions. Thus, these

### Needs of the Field

- Identifying unanticipated factors influencing situations and issues;
- Enabling researchers to study the complexities of life experiences;
- Giving a holistic picture of the phenomenon studied;
- Incorporating the perspectives of the people studied; and,
- Providing further insight into experimental and survey designs.

*This study also highlights the importance of the qualitative methodology and longitudinal approach to gathering information. The SSI Family Impact Study addresses the use of qualitative research methodology and examines its effectiveness in meeting the needs of the field as identified by Maxwell (1990).<sup>2</sup>*

<sup>2</sup> Maxwell, J.M.A. (1990). Gaining acceptance from participants, clients, and policy-makers for qualitative research. In Fetterman, D.M. (Ed.) *Speaking the language of power: Communication, collaboration and advocacy*, Washington D.C.: The Falmer Press.

<sup>3</sup> E.g., Children Receiving SSI annual reports from the Social Security Administration, Office of Policy, Research, Evaluation and Statistics, Division of SSI Statistics and Analysis.

supports can develop more effective treatment and service plans, and more efficiently use their limited resources. The experience of families is viewed not as an ultimate outcome issue, but as a quality of life issue. The SSI Family Impact Study report captures this qualitative shift as it presents data gathered directly from families, in their own words. By remaining close to the words of the families during analysis, and presenting those words throughout this report, we have remained as true to the data as we believe is possible.

This report is organized into seven major sections. *Section 1: Introduction*, includes the background of the SSI legislative changes and the purpose of the SSI Family Impact Study. *Section 2: Methodology*, addresses design, structure of inquiry, analysis plan, building a research team, and recruitment and retention issues for longitudinal design. *Sections 3 and 4: Description of Sites and Families*, summarizes the demographic data of the families and sites participating in the study. *Section 5: Key Findings*, summarizes the data and perceptions collected and is presented as findings related to children and families, findings related to the SSI benefits and process, and findings related to Medicaid and health care. *Section 6: Summary and Implications*, offers a thematic overview with implications for families, for local mental health program support and family service organizations, for state and federal policy implementation and for evaluators. And, *Section 7: Future Directions*, offers areas for further investigation and hopefully provides information for thoughtful debate and consideration.