# Executive Summary

## Supplemental Security Income (SSI) Family Impact Study

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## Background

In 1996, a new federal law was passed that made significant changes in the Supplemental Security Income (SSI) program. These changes altered the definitions and procedures for families with children with serious emotional disturbances to receive cash benefits on behalf of these children. For many families, these changes mandated reviews to re-determine the eligibility of children with emotional or behavioral disorders who previously qualified for SSI benefits, thereby jeopardizing an important support to families.

In response to these changes, the Research and Training Center for Children's Mental Health at the University of South Florida, with support from the federal Center for Mental Health Services, SAMHSA, and the National Institute on Disability and Rehabilitation Research, initiated a study to increase understanding of the impact of this policy change on families. Specifically, this study was designed to complement some of the more cross-sectional quantitative research on the impact of the SSI changes by using qualitative research methodologies to study a sample of families over time and in depth. Such an approach goes beyond looking at aggregate numbers and seeks to provide an understanding of the impact of the policy change in more human terms.


The Full SSI Report and this Executive Summary are available from the Research and Training Center for Children's Mental Health, Department of Child and Family Studies, Louis de la Parte Florida Mental Health Institute, University of South Florida, 13301 Bruce B. Downs Blvd., Tampa, FL 33612-3807, 813-974-4661 and can also be found on our website at http://rtckids.fmhi.usf.edu

The study followed 40 families over a 22 month period, through a combination of in-person interviews and telephone interviews every three months. The families participating in the study came from rural eastern Kansas, New York City, and west central Florida. All had received a letter from the Social Security Administration (SSA) either in the spring or summer of 1997 notifying them that their child's eligibility for benefits was being reviewed. In addition to the 40 families who participated in the individual interviews, a series of focus groups was held in the three communities to gain additional perspectives on the impact of the SSI changes.

The study used a longitudinal design, making it possible to describe the sequence of events that happened after the families had received the letter from SSA. However, there is no comparison group (e.g., families with a child with a serious emotional disturbance who did not receive letters from SSA), and it is not possible from a scientific standpoint to clearly establish a causal relationship between the policy change and outcomes in the family. However, many of the families reported on what they believed the effect of the SSI changes to be, and, as researchers, every attempt was made to capture as accurately as possible the views of the parents involved. Therefore, while this study is basically a descriptive study it does include the views of the parents of the effects upon them and their family members of the changes in the law. The quotes included are illustrative comments from parents who participated in the study.

# FINDINGS

## Findings Regarding Who the Children and Families Are

> *"He has a lot of problems. He's ADHD and bipolar, and that's why he's on SSI in the first place. Because he's on medication and needs to see a psychiatrist. He has been since age 5. The psychiatrist said it would change by the age of 12 but it hasn't."*

- The children in the families had severe emotional and behavioral disorders and the change in eligibility and loss of SSI did not change their need for services. The SSI eligibility criteria were changed in the law in response to allegations that the procedures previously used allowed children and families to "fake" disabilities in order to qualify for SSI benefits. However, this study found no evidence to support allegations of this abuse;
- Most of the children were enrolled in special education classes;
- These were families in which not just one child but often adults and siblings had major health or mental health problems;
- In over 60% of the families, the primary caregiver was a single mother;
- The families experienced consistently high stress, with problems not only in the health and mental health areas but also related to income and employment, housing, safety, family stability, transportation, and substance abuse.

> *"His father's going through depression. And, he's been physically hurt and the medications he's on are making him very moody. Well, he says he can't deal with any stress. The kids stress him too much. Any little things stress him and he's gone out drinking. And he's gone all the time and I just told him, 'That's it, either you move out or you can get some help.' And he didn't want to move out so I tried to physically remove him."*

## Findings Regarding the Importance of the SSI Financial Benefit

- The SSI cash benefit represented an average of 41% of the families' total income, with a range of 15% to 100%;
- Families reported that the SSI income was generally incorporated into the overall household budget, often helping to pay a portion of the rent, utilities, and such essentials as clothes and shoes for their children. The cash benefit also helped pay for transportation, medication, educational supplies and childcare, and helped their child participate in "normal" activities, such as school outings, and community recreational activities;

> *"We use it to stay afloat, mainly to pay bills. Still trying to pay off debts...his trip this summer and then if anything else...like car transportation problems...or medical bills that end up on your credit card, or prescriptions, things like that. We're trying mainly to stay out of debt. I do spend money on the kids, mainly it's just a little bit of this and that. When they need clothes. Mainly the usual stuff. We didn't buy a new boat or anything like that."*

- SSI was particularly important as a stable source of income since the primary caregiver's employment status and the status of those making financial contributions to the household varied throughout the course of the study.

## Findings Regarding the Impact on Families of the SSI Changes and Process

> *"It's an emotional strain that they put you through. You sit there and you wonder, all right, what is the best thing for him. Of course, I couldn't take him off the medication, for heaven's sake. And you sit there and, I'll tell you, yet get to the point that you want to give up."*

- Although the worst fears of child and family advocates – that the changes in the law would result in children being placed outside their homes – was realized for only one of these families, the families did report an increase in turbulence and crises leading to negative changes in the child's well-being and the overall family quality of life;
- Families reported not only suffering stress from the loss of benefits but also from having to wait for the outcome of their appeals;

> *"He worries about money. He don't know what amount of money he worries about, he just worries about money. I tell him 'You don't have to worry about money, let mommy worry about it.' But he always worries about it."*

- Many families experienced an impact on their ability to access mental health care, including visits to therapists and doctors, and receipt of medications;
- Families experienced a loss of ability to provide "normalizing" activities for their children, such as participating in formal recreational activities and school outings. Parents also had less time to spend with children as they worked additional hours or spent time handling the review process;

> *"He (doesn't have) real understanding about stuff like that, but you know it hurts like hell because he knows I wasn't able to enroll him in as many summer activities as I did before with our recreational center. They both caught me crying several times because I'm trying to get caught up and we have no money for some of our bills so therefore there can't be no 4th of July."*

- About half of the families report that their child's behavior had worsened over the course of the study;
- Some families reported positive outcomes of the process, such as learning how to become more effective advocates and feeling more independent. Most families, however, reported that retaining the benefits gave them greater peace of mind, primarily due to the assurance that their child had medical coverage.

> *"A lot better off in some sense because I'm more independent and I don't have to wait for the check to come in. But it's just lack of income, not being able to see a doctor. It did help me to go to school, that's about all it's done."*

## Findings Related to Medicaid and Health Care Coverage

- The main reason that most families appealed was the potential loss of Medicaid. Parents reported that this was a critical benefit of SSI;

> *"He lost Medicaid, too. Now he cannot continue with his treatment and his medication. I had to interrupt all services that he received because he lost his Medicaid. He can't get his medications and he can't get therapy. He is not doing well as a result of not getting his medications."*

- Health care coverage is tenuous for many of the families, and across sites many parents were without health insurance or health care coverage of any kind. As a result, parents often avoided seeking primary and preventive care, and waited until crises were so severe that they had to use the emergency room.

> *"When he (husband) gets sick, he just doesn't go to the doctor, until, you know, it gets really bad. We pay out of the pocket. That's a big part of our bills."*

## Findings Regarding Coping Mechanisms of Families

> *"I've been appealing every time they send me a notice stating that he's going to be cut off. They reinstate him for the next year, then I appeal again, they reinstate him...it's one of those types of things, like it's an ongoing battle."*

- Parents were not passive in response to the loss of SSI. They struggled with decisions about whether to appeal, knowing that if they appealed and lost they would have to repay the money that they had received while the appeal process was taking place. Those who decided against second and third appeals frequently commented that they did not believe that they would prevail, or did not want to endure the stress of further appeals;
- Families became better navigators of public supports;
- Some families indicates that through the process they confirmed their own internal strengths, and validated their resiliency;
- Both informal and formal helpers were major sources of support. However, the support was often inconsistent.

*"My mother helps me like every month. She'll do shopping for me. And, I don't want to be taking from her because she's old. She's retired. Instead of me helping her, she's helping me. I feel embarrassed, so I don't always ask."*

## Findings About the SSI Process

*"I was confused, first of all. Then, second of all I just couldn't believe it. And the explanation they gave didn't even fit the description. So, I was amazed that they were even doing that. And I didn't accept it."*

- Families were taken by surprise and distressed when notified that their child's eligibility for SSI was going to be reviewed;

  *"I was like in shock. They bring SSI all these years. Why are they gonna stop it now? Ain't nothing's changed. They are still in special education. They are still slow. So why they stop it?"*

- While the decision to appeal or not appeal was made for a variety of reasons, very few sought and received legal help with the process;
- Families found the SSI review process difficult and confusing, and particularly struggled with the issue of whether to retain cash benefits during the appeal process, knowing that they would have to repay the benefits if they lost the appeal;

  *"I was scared. I didn't want to get into worse trouble. I was told that if I appealed, they would keep sending checks until we went to court, then I would have to pay back on what I owed them. So I was real scared of that."*

- Experiences with state and local SSA offices generally proved problematic and confusing for parents;
- There was both a general feeling of distrust among families of the SSA's ability to make an accurate determination of eligibility and a pervasive belief that SSA was not very knowledgeable about the connection between the SSI cash benefits and Medicaid;
- The SSI review/appeal process was lengthy, requiring a lot of 'waiting and wondering' that caused increased stress.

  *"Until you do the paperwork, you have no concept of paperwork. I mean, I was in the military. I thought they had paperwork. I've got banana boxes full...and then they want to see the paperwork from 8 years ago when he went to the emergency room, over the past ten years...and then you're denied because you don't have the paperwork."*

# Conclusions and Implications

The SSI Family Impact Study has examined the impact of a major policy change in a program designed to provide economic assistance to low-income families with children who have a serious emotional or behavioral disorder. The policy change was partly precipitated by a concern that children were receiving the benefits who in fact did not have significant emotional disturbances. However, within the sample studied in this project, there was no indication that this was the case. The children all appeared to have serious problems of considerable duration and were receiving special services both in the mental health system and the education system.

Overall, the primary finding is that from the perspective of the families affected, the new policy had negative effects. Some of these effects are to be expected since the SSI cash benefit constituted an average of 41% of the income of the families in the study, all of whom were low income and had very precarious financial circumstances to begin with. There were consistent reports that the policy change created great stress and hardship on all family members, that it often led to a cascading series of negative events, that families experienced problems in continuing to access needed mental health and health services for their children, and also that they were often unable to continue providing some of the normalizing supports that are important for children.

Although the economic impact on the families was great, many families felt that the loss of Medicaid benefits was an even more serious problem than the loss of income. Families responded initially to the news that their child could potentially lose his/her SSI eligibility with surprise and shock, and struggled throughout the study to understand the rules and processes involved. Many families who lost benefits appealed the loss. While some were successful in overturning the initial decision, a major barrier to appealing was the rule that indicated that while families could continue to receive cash benefits during the appeal, they would have to repay the money if they lost their case.

Despite the predominantly negative events that followed this policy change, parents made heroic efforts to keep their families intact and in only one instance did a child end up leaving the home. Some parents reported that the entire process had enhanced their sense of personal strength and resilience, and left them feeling more independent and capable. Parents also reported benefiting from a range of informal and formal supports. Overall, however, parents primarily reported that the change had very negative effects on their entire family, despite their best efforts.

Based on the parents' reports, some of the negative impact could have been alleviated. The families reported frustration at receiving incomplete or inaccurate information, and at not being able to access knowledgeable people to assist them. They reported extended delays in the appeal process, and disappointment that appeals were sometimes based on very cursory assessments of their children by individuals who had just met their child. The relationship between the receipt of the cash benefit and the continued receipt of Medicaid seemed particularly unclear, and this created an extra problem for the families.

Overall, the information gathered from the in depth study of this group of families first of all raises questions about the wisdom of the policy change. It clearly created a great hardship for families who were already fragile in many ways, and who had children with serious problems. While it is not possible to document specifically the full impact on the families, the preponderance of evidence from the families suggests that this is truly a group of needy families with children with serious problems, and that removing the basic economic support and health care coverage adversely affected the family, often being followed by a series of crises and negative events.

It is also apparent, from the view of the families, that the manner in which the policy change was implemented added to the stress and hardship, and perhaps to the negative outcomes. It is essential when changes are made to long-standing policies that there be clear communication about them, that there be ready access to knowledgeable people to assist the affected families, that procedures be easily understandable, and that decisions be made after thorough review and in an expedited manner.

While this study provides an extensive report of the perspective of a sample of families, it is important that additional research be done to examine the effect of this policy change on children and families. This study has utilized a longitudinal approach with a qualitative methodology that permits gathering comprehensive information over time from a limited sample. Such a methodology is particularly helpful in allowing policy makers, advocates, and researchers to look beyond the numbers to enhance their understanding of the impact of policy changes. It is hoped that such an approach will routinely be incorporated as a complement to more traditional quantitative approaches in efforts to understand the impact of policy.

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