



SECTION 5

KEY FINDINGS

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This section provides a summary of the key findings of the SSI Family Impact Study along with supporting data and perceptions provided by the families who participated in the interviews. Key findings are presented in six major areas:

- Findings Regarding Who the Children and Families Are
- Findings Regarding the Importance of the SSI Financial Benefit
- Findings Regarding the Impact on Families of the SSI Changes and Process
- Findings Related to Medicaid and Health Care Coverage
- Findings Regarding Coping Mechanisms of Families
- Findings About the SSI Process

At the time of the initial interview and throughout the two-year study period, all families were in various stages of the process for the legislated SSI review of benefits. As noted earlier, all had received a letter from the SSA sometime in the spring or summer of 1997 notifying them that their child's eligibility for benefits was being reviewed. Based on that review, many families were denied benefits for their children and chose to appeal. These families were in various stages of appealing, with a few already receiving notification that their child's benefits would continue.

Findings Regarding Who the Children and Families Are

FINDING 1: These were children with 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 because of allegations that the system's use of the Individual Functional Analysis (IFA) allowed children to "fake" disabilities—especially emotional and behavioral problems in order to qualify for SSI benefits. However, this study found no evidence to support allegations of this abuse.

"I've called the police on him 3 times for throwing things at me. He doesn't have a bedroom door anymore. It came flying out in one of his little rages. He broke his closet doors, if you'd like to see that room? He had one of his fits this morning. I called the police on him for his rages because he throws things at me, he cusses at me, you name it."

These were children with serious disorders; most dually diagnosed with attention deficit hyperactivity disorder (ADHD) and with another diagnosis based on the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV), with 62% of these children receiving an ADHD diagnosis. It was most prominent in Kansas, where 83% of the children were reportedly diagnosed with ADHD or dually diagnosed with another diagnosis. Those children with ADHD were described as having behavioral problems that affect life at home and at school that noticeably limit their interpersonal skills. Other parents reported that their children had a severe behavioral

or emotional disorder. Unable to identify a specific diagnosis, one mother described her child as “emotionally handicapped,” while another described her son as having undetermined “fits of rage and blackouts” stemming from a childhood rape.

Children were also reportedly suffering stress related to neglect and abuse. Parents reported that their children were angry, depressed, or had trouble sleeping. They also experienced side effects from their psychotropic medications, and exhibited difficulty learning and functional limitations. One mother described how her nine-year-old child was unable to dress himself. Another boy had frequent blackouts and nightmares after being sexually molested at age six. In some cases, emotional and behavioral problems escalated during the course of the study. Several children in each site were dually or multiply diagnosed. In addition to ADHD, they were reportedly diagnosed with learning disabilities, speech problems, intermittent explosive disorder, oppositional defiant disorder, post traumatic stress disorder (PTSD), and/or bipolar disorder. Two parents reported that their children were depressed to the point of suicidal ideation, while two had seizure disorders. Others had been diagnosed with obsessive-compulsive disorder (OCD), while one was multiply diagnosed with bipolar, intermittent explosive disorder, dyslexia, dysthymia, and suicidal ideation. Another had been misdiagnosed as mentally retarded. One child had reportedly been deprived of oxygen at birth.

“When he’s on medication, he pretty much slacks, he’ll pretty much be more cautious. But when he’s not on meds, you could see him slowly drifting into where he doesn’t care. He’s very, very hyperactive. He’s too moody. He doesn’t care about his life. He says when it’s my time to go, he’ll go. That’s the way he feels.”

“We put him back on Ritalin and it didn’t work really. So out of control, even in school the teacher said ‘no, this ain’t working.’ And, I knew it wasn’t working, just answering back and cursing and had the last word all the time. So we switched him back to Risperdol that he was on before and it got better. Not completely better. We’re still working on a lot of temper tantrums and all that stuff. But that was the only change that we tried but it wasn’t a good change.”

In addition to dealing with emotional and behavioral problems, many of the children in this study suffered physical disorders, diseases and conditions, both acute and chronic. Several children were dealing with major health issues, such as cystic fibrosis, seizure disorders, heart conditions, cerebral palsy, and tuberculosis. Children also reportedly suffered from asthma, chronic stomach problems, migraines, allergies, and infections.

“He has been in the hospital (since last interview). Since he has been out of the hospital, he has been to the emergency room twice, because we are trying to get the medicine adjusted to him. But on the whole, when the medicine is working he is doing very well.”

Parents were not always clear about their children’s diagnosis, with a few being unable to specify the diagnosis for which their child was receiving SSI benefits. One mother reported that the SSA listed her son as receiving benefits for ADHD, when he actually quali-

fied because of Tourette Syndrome. Others recalled terms such as “secondary disability” “language disorder,” and “anger disbursement” as being applied to their children.

“He has a lot of problems. He’s ADHD 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. He said it would change by the age of 12 but it hasn’t.”

Reports of the children’s behavior fluctuated beginning in the third wave of interviews. Some were showing improvement, while most were worsening or continuing in old behaviors at home and in school. While some children were improving with medication and other services or programs, others were dropping out of school and relationships with parents and schools were becoming strained.

“He wanted to kill himself and kill other people and try to jump out of pickups. . . he was like in the 2nd grade and that’s when I was really having trouble with him.”

“He’s still got some behavior. He’s really no more different than any nine-year-old boy. He’s rambunctious. He’s way over powered. If he don’t take his medication I guarantee you I can’t be around him. He’s improved so much. He does bowling now.”

“I characterize his behavior as moody, angry, very angry boy. He does things before thinking. So he is more apt to, let’s say, go in front of you without looking to see if anybody is coming.”

“His behavior has deteriorated. His academic skills went straight down the tube. Whatever he did know he has lost. Basically he was a 14-year-old as far as birth age, but he was functioning as a 10-year-old. Now he is 16 years old functioning on a 9.”

“And my child was in therapy since the age of four. So, he went to regular education after third grade and then he started acting out, got very withdrawn and depressed, and the school requested that the committee on special ed. evaluate him. So, automatically, they labeled my son as severely emotionally disturbed. I had to take him to a number of evaluations and I recall also that in one session my son talked about suicide. Attempted suicide. He was seven. He attempted suicide, so he automatically got labeled and diagnosed with his depression disorder.”

FINDING 2: Most of the children experiencing the review were enrolled in special education classes.

“He’s been in the special ed. ever since he was in the second grade. Since junior high he was in regular PE and maybe another class. Maybe two classes during the whole day were outside of [special ed] class. Pretty much most of the rest of the time he was in special ed.”

At the beginning of the study, more than half of the children in all three sites were enrolled in some kind of special classes, including special education, alternative school, or classes for children with serious emotional disturbance (SED) or learning disability/be-

havioral disorders. Others were being home schooled or were receiving extra help with reading and math to keep up in regular classes. Throughout the course of the study, parents frequently reported that their children were struggling academically and/or behaviorally, with some being held back a year and others expelled or otherwise removed from school after repeated problems.

“He keeps getting suspended. I think the school is going to go ahead and send him to an alternative school. He’s in the ninth grade. He’s only been ten days out of the whole year, maybe 15 at the max. He keeps getting himself in trouble. Then, he won’t go to school. And, when I force him to go to school he keeps getting in trouble. He’s in the SED program. They’re supposed to be able to handle this situation but I don’t know why they can’t, because that is a special setting, then they want to send him to a different special setting.”

There were few changes during the course of the study in the children’s special education status or enrollment in school, which further supports the severity of these children’s needs. In a few instances, children were moved from regular classes to special education, with placements in SED classes or other structured programs. It was rare for children to demonstrate a reduced need for special education. However, one child in Kansas transitioned from alternative school to public school with an IEP and para-professional support.

“No more special school. We did a blind leap of faith and put him in [regular school] with support. And he’s in a couple regular classrooms and he’s in special education. He’s in special education with regular para support in there. In the first 12 weeks he’s made As on his spelling tests. And I haven’t even had to go to school once for him.”

“A Size 7 Agency is a therapeutic program, which basically teaches them about behavior modification, conflict resolution; they monitor the medication making sure it’s taken when it’s supposed to be taken. In the meantime they have given him a person for home instruction and it’s the best thing that ever happened to him.”

“I never wanted him in special ed. ‘cause really the work is too easy, but mental stability is better for him, like he can think better and clearly in a class of 15 children than in one of 32 children.”

FINDING 3: Children showed behavior that was highly variable but a new diagnosis was rarely given.

The longitudinal nature of the study allowed snapshots in time that reflected how variable the children’s behavior could be from one month to the next. Despite these variations, only a few children received new diagnoses throughout the course of the study. One child had undergone a full diagnostic evaluation and received a new diagnosis, including ADHD, Pervasive Developmental Disorder, and an unidentified psychotic disorder. Two children experienced a change in diagnosis from ADHD to SED and Oppositional Defiant Disorder, respectively. Another child began struggling with depression, while yet another was undergoing reevaluation.

“First they (schools) were complaining because he was sleeping all day and then they were complaining when I took him off the medications because he was too hyper, or ticking or whatever. Then we had transferred to a school and she didn’t know that he wasn’t on any medication and he was making student of the month.”

“And then they diagnosed him with an anger disorder now. And it has something to do with the ADD and ADHD. It interferes with a lot of things that he does. He seems to get in trouble. And then the anger disorder right on top of it.”

“They haven’t really diagnosed him, they’re saying he has Attention Deficit Disorder, but he doesn’t have the hyperactivity. Now they are saying his energy is focused one way then it’s focused another. They really don’t have a diagnosis for him.”

FINDING 4: These were families in which not just the one child, but adults and siblings had major health or mental health problems.

During the course of the study, primary caregivers clarified their health status and that of their immediate and extended family. Primary caregivers had been diagnosed with diabetes, emphysema, kidney stones, arthritis, asthma, and cataracts. Some caregivers were suffering from emotional stress, while other members of their families also suffered from physical and mental/emotional problems. Several parents reported that siblings of the focal child had physical disabilities or had been diagnosed with ADHD or other emotional/behavioral problems. In Kansas, one mother had survived cervical cancer, while another was going through a high-risk pregnancy with twins.

Throughout the course of the study, these families continued to experience the loss of loved ones and both acute and chronic illnesses, ranging from fibromyalgia to heart disease. In the face of these disabilities, primary caregivers reported struggling to keep their disability benefits and to obtain equipment and services for other family members. One primary caregiver lost her disability benefits after an evaluation and another was refused a wheelchair for her husband. They also struggled to obtain medication, dental care, and medically necessary surgeries.

While SSA benefits for adult family members were not as prevalent among families in Florida and New York as they were in Kansas, three primary caregivers in Florida described themselves as physically disabled. One was on SSI as an insulin dependent diabetic, while being simultaneously enrolled in a methadone program. Others suffered migraines, eye problems, immune system disorders, and rheumatoid arthritis. Siblings and fathers were also receiving disability benefits and extended family members suffered health problems, including severe arthritis, a heart condition, alcoholism, diabetes, ulcers, kidney failure, high blood pressure, and glaucoma. Emotional problems, including stress and depression were also reported.

“They [a shelter for women] showed a film that night and they talked about different types of abuse and the effects that it has on people and I came out of there just overwhelmed because there’s not one type of abuse on that file that hasn’t been at least once in my life. I came out of there feelin’ well, self-destructive.”

“We are all at different stages of depression, but we all seem to be able to help each other through it.”

In the initial interview most families in New York did not report any health-related problems, either physical or emotional. In later interviews, a few reported a variety of physical ailments, both major and minor, including high blood pressure, diabetes, obesity, high cholesterol, migraines, and depression. In two families, the primary caregiver or other family member had HIV/AIDS.

“My husband needs to take a medication in the morning and another one at night. You see, his heart is really big. He has an operation where he has a machine and he can die at any minute.”

“She’s a diabetic. Her doctor wants her to go ahead and retire. She’s getting ready to go on disability. She’s 42.”

“I’ve gotten worse. My back has gotten worse. My leg has gotten worse. They’ve changed my medications because I suffered a severe anxiety attack. I’ve had a couple of them. It’s affected my right arm, the one I broke 5 years ago in an accident, and it never bothered me before. The arthritis has gotten worse, and they said that I have joint disease.”

“I have emphysema. I go to the clinic and they have a compressor there. So see, that is why I am getting worse, a lot of times I just lose my voice and I don’t know why.”

Families in Kansas distinguish themselves from those in the other two sites, with someone in every family other than the focal child receiving death or disability benefits from the SSA. In some cases, children were receiving a portion of their father’s physical disability benefits. Three families were receiving SSI death benefits, after the child’s father passed away. Five out of 12 primary caregivers were receiving SSI benefits for a physical disability that prevented them from working full time. Several siblings were also receiving benefits for physical, emotional, and mental disabilities.

Kansas Families – Receipt of SSI Other Than by Focal Child

Family #1: Receiving SSI death benefits

Family #2: Grandmother receiving SSI benefits for physical disability

Family #3: Grandmother receiving SSI benefits for physical disability; biological sister receiving SSI benefits for emotional disability

Family #4: Ex-husband of PCG receiving SSI disability benefits – son receives payment

Family #5: Family receiving SSI death benefits after husband/father dies

Family #6: Second child receiving SSI benefits for emotional disability

Family #7: Mother receiving SSI benefits for physical disability (high blood pressure)

Family #8: Father and family receiving SSI benefits for physical disability. Father dies and family receives SSI death benefits.

Family #9: Mother, father and two sisters receiving SSI disability benefits. The sisters for physical disabilities (Cystic fibrosis)

Family #10: Younger son receiving benefits for mental retardation. Ex-husband receiving SSI benefits for physical disability – sons receive a portion of this each month.

Family #11: Mother (rheumatoid arthritis) and sister receive SSI benefits for physical disability

Family #12: Mother receives SSI benefits for physical disability (rheumatoid arthritis.)

FINDING 5: Most families were single parent homes, where the primary caregiver was the child's biological mother.

Over 90 percent of the primary caregivers participating in the study were female, ranging in age from 21 to 61, with over 60 percent single parents. The majority of these primary caregivers were the child's biological mother.¹ In a few instances, the primary caregiver was a biological grandmother, while in two cases it was the biological father. Live-in boyfriends and fiancés were also living in some family homes, with the specific composition changing over the course of the study. Siblings, extended family members, and the parents' significant others were often moving in or out.

"It (loss of SSI) really doesn't have an impact on the kids, but it has an impact on me because I'm the one doing all the running around...But it's hard on only one parent, taking care of all these things that need to be met."

FINDING 6: These were families experiencing consistently high stress with co-occurring negative events and challenging existing circumstances.

During the SSI review and appeal, families experienced a variety of events that put stress on the home and drained the energies of primary caregivers. Parents were struggling to cope with their children's behavioral problems, which were manifested by acting out in school and at home, sometimes aggressively. In some cases, siblings were suffering with emotional and behavioral problems and/or going through the SSI review and appeal themselves. Primary caregivers and other family members were dealing with medical or emotional problems of their own, with several parents being worried about losing their own disability benefits and squeezing the family budget even further.

"I had to use my retirement money 401K to get a bankruptcy. My husband was in jail for 6 months...with the child support he just got out last Monday, after 6 months."

Mothers and fathers lost their jobs during this time and suffered from depression, poor health, or other disorders. Husbands and boyfriends were being injured on the job or fired. Unemployment benefits were running out with no other financial resources available. Changes in employment also brought the temporary loss of medical benefits or uncertainty about coverage in some families. Parents on welfare were facing the loss of those benefits due to welfare reform legislation.

Family members struggled in their interpersonal relationships, with mothers suffering domestic abuse or unstable relationships with significant others. Other families experienced random events, such as the primary caregiver being arrested in a case of mistaken identity and a boyfriend being attacked and requiring hospitalization. Families were also struggling financially and living in unsafe neighborhoods. A few were dealing with the stress of recent deaths. Immediate and extended family suffered a variety of chronic and acute health problems. During the course of the study, one family lost their

¹ The SSA's Children Receiving SSI December 2000 report presents similar data: Over three-fifths of the children receiving SSI (62%) were living in one parent households; and, of the 62%, nearly all (95%) lived with their mother.

father suddenly to a brain aneurysm. One family lost a grandfather due to poor medical care, while another lost a grandmother to a heart attack.

“Well, we thought he had a heart attack and then he’d been in and out of the hospital after that for about three months and now he can’t drive anymore and he was to wear a catheter and he’s got Parkinson’s Disease.”

During the study, three families were dealing with child molestation by a neighbor. One of these families was also dealing with felony criminal charges against an older brother caught in a sexual act with a younger brother. Another mother was forced to give her newborn twins up for adoption and lost another child to foster care after failing to provide a stable living situation.

“He pushed me and one of my arms was half black and I took him out with the police. My daughter was in Puerto Rico and she got back the other day. It is just my kids and I. I don’t want to know anything else about him. My children come first.”

Support systems were often in flux, resulting in broken relationships with friends and family and subsequent isolation on the part of these parents and their children. In one case, a mother’s best friend became seriously ill and nearly died from an illness affecting her brain. In another family, the sons received a “goodbye letter” from their biological father, who decided to break all ties with them.

“He’s [dad] 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. You know. 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.”

Families reported having other legal problems, including abuse/neglect cases, bankruptcy, child support cases, and divorce. In one case, a child’s parent was in jail. In addition, family members suffered car accidents, dealt with teen pregnancies, alcoholism, and struggled with transportation. Children were also periodically dropping out of school or experiencing difficulties due to their behavior and/or academic performance.

“God I hate it, when I had my heart surgery, and on Christmas day I started having chest pains and they had to rush me by ambulance back up there. Thank God my son is a paramedic. The only way I could come home is if I had someone living with me. The kids’ mom stayed with us for four months and we actually made it! They say now that I might have cancer and my son calls me all the time.”

“She’s drinking a lot more than she used to. That’s a stress on me I tell you. She can come unglued at anytime. She might have to start counseling because she started drinking at work and they’re going to come down on her. They’re going to make her get help.”

“Yes, she is terminally ill. She has AIDS, already for 11 years. And right now her health, she is in a wheelchair now. . . I actually just came from the hospital, after I went to the clinic, and then I took her back home and came here to meet you. She is really here by the grace of God.”

Findings Regarding the Importance of the SSI Financial Benefit

FINDING 8: SSI cash benefit represented an average of 41% of the families' total income.

Families reported that the SSI cash benefit represented a low of 15 percent to a high of 100 percent of the families' total income.² Families also reported variability in amount of the SSI check they would receive from month to month depending on their reported income.

Lets see, normally we get \$400 bucks...so around 40% of the income was SSI. I mean that's a big piece of your income. Not knowing if it's going to be 20% or 40%."

FINDING 9: Families typically used the SSI cash benefits as part of the household income, to meet basic needs, pay bills, and cover expenses.

Parents expressed fears concerning how they would cope financially without the benefits, often resulting in feelings of frustration and depression. Families reported that SSI checks were generally incorporated into the overall household budget. The money helped to pay a portion of the rent and utilities. Some reported they were in jeopardy of losing their home. The loss of the cash benefit had a significant impact on their ability to afford essentials such as clothes and shoes for their children, a particularly large expense in families where the child was growing rapidly. Parents reported that there was less food or that the quality of food they were able to buy had worsened. The cash benefit also helped pay for transportation, medication, and childcare.

"We use it to stay afloat, mainly to pay bills. Still trying to pay off debts...his trip for car racing 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."

"We lost our van, because we were using the kid's stuff to pay for the van.. To drive them around. Well, anyway we lost that."

The SSI money helped to stretch the family budget, which allowed parents to allocate some of the funds for the children's recreational activities and entertainment. Since the majority of these children were diagnosed as having ADHD, parents felt it was necessary to keep the children busy and involved in activities. The SSI money

² According to the SSA Children Receiving SSI December 2000 report, for 39% of the children in a one-parent household, that parent had no reported income (other than SSI payment) and 30% of the children were in homes with under \$200 monthly income.

allowed children to engage in activities with their peers, including school outings and events, movies, and swimming at the public pool in the summer. It was also used to purchase uniforms and equipment, so that the children could participate in sports at school, and paid for educational materials, including books, computer programs, and tutors. Family activities also became more limited, with parents less able to take care of themselves or enjoy recreation that would relieve their stress. In one instance, a family used the money to make home repairs after their son acted out aggressively and broke or damaged the structure or belongings.

Parents were not allowed to save the money or put anything away for a “rainy day,” or save for their child’s educational future, as that was counted against the child’s monthly benefit.

There was also less time to spend with children as parents worked additional hours or spent time handling the review process, and a persistent fear of the loss of Medicaid. In some cases, the added stress resulted in increased fighting among family members. Family quality of life was also negatively impacted, with parents commenting that they were unable to pursue avenues to improve their lifestyle or plan for the future. One family experienced financial catastrophe, leading to eviction and filing for bankruptcy.

The few families who won their appeal or successfully reapplied for benefits received large sums of money for unpaid benefits, which they referred to as “back pay.” This money was used to buy furniture for their child’s room, purchase VCRs, recreational camping equipment, and for older children, items that he or she would need to live independently. Near the end of the study, one child in Kansas was living independently and relying on his SSI benefits to pay for his living expenses.

“Now if they go way back to June [in back pay], I want him to get like dishes pots and pans and silverware. You know, things he’s gonna need for when he gets out on his own. ‘Cause’ we got the shop to store stuff in until he graduates and moves. And he just does not seem to think that way.”

“I used it for rent and utilities and groceries. . . because we don’t get food stamps. We’re not on welfare.”

In all Kansas families the impact on children was reported to include a decreased ability to afford recreation and other kinds of activities. Families that *were not receiving* SSI cash benefits for the focal child throughout most or all of the study and *were not receiving* those benefits at the end of the study reported being unable to afford clothes for school and Christmas presents. Others were unable to afford therapy or other needed services.

FINDING 7: SSI was important as a stable source of income.

Despite the potential variability in amount from month to month, for all the families, the SSI cash benefit had been a stable source of income. The primary caregiver's employment status and the status of those making financial contributions to the household varied throughout the course of the study. In the initial interviews several primary caregivers were working part-time, with a few working full time. Only one primary caregiver was working full time in Kansas. Four mothers in Kansas were unemployed and receiving disability benefits, while another was unemployed while not on disability. In Florida, those families with employment income were relying on the husband, grandfather or male significant other as the source of that income. Most families in New York had some employment income at the time of the initial interview.

“He was drawing \$130 from his dad [disability] and then he got his SSI. I know it was supposed to be 4 [hundred] something he was supposed to be getting.”

Depending on the employment status of the parents and other adults contributing to the household, the portion of the expenses covered by these sources varied throughout the course of the study. Several families were living on income from a combination of sources, including employment, disability or death benefits, their child's SSI, child support and public assistance, with two receiving food stamps. Two primary caregivers in Florida were relying on employment income from a teenage child. In New York, one mother was receiving disability benefits for both her and her child, along with public assistance and child support. A few were receiving financial help from extended family. It should be noted that for many of these families full-time employment was not a viable option because of the demands of caring for their children with special needs.

“Since my other son is on welfare, so he get food stamps. So, I take the food stamps that my son get and I put it, you know what I'm saying.”

“Right now my son is working, he works as a security guard. . .right now I'm receiving welfare for myself.”

Only four families had the benefit of being dual income households, where the father or grandfather was working full time. In three of the two-parent households, the father was unemployed and receiving disability benefits, with one being unemployed without benefits.

“They said that I'm allowed to make up to a certain amount in the household [without decreasing the death benefits].”

In a few cases, primary caregivers became unemployed during the course of the study, due to a physical disability or the loss of a job. One primary caregiver in Kansas lost her full time employment when her employer went out of business. The income was replaced temporarily by unemployment benefits and then by an income tax refund of \$3,000, which covered the family until the mother could find a new job. In another family, the father landed a better job with increased pay. Income levels were also periodically increased or decreased based on the status of a mother's relationship with her husband or live-in boyfriend.

“I don’t know where he is now. I haven’t seen him in...I guess he doesn’t have a job. If he don’t have a job, they can’t get a check. He can’t get a check for him [their son].”

“Today was my last day where I’m working at Betten Fields. I’ve been at Betten Fields for almost 9 months. They went out of business today.”

“I’m working now 33 hours [a week]. I probably changed clients since the last time we talked.”

“I’m working. I think I got a pretty good job. I’ve been with this company for about two weeks. I’m there through a temp agency, but I think they might keep me, I hope. I only make \$8.00 an hour, so I bring in \$320. That’s why they kicked me out, because my income’s so great.”

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

FINDING 10: Although the worst fears of child and family advocates—that children would be placed outside their homes—was realized for only one of these families, there was an increase in turbulence and crises leading to negative outcomes and changes in the families’ quality of life.

“Basically I have a choice: I either keep my transplanted son alive and buy his medicines. And without them he dies. Or I buy the medicine for my son who needs it so that he doesn’t destroy my house and my family. You get torn between who gets what. And that’s why I said the medical is astronomical to us. That’s where it can either make you or break you.”

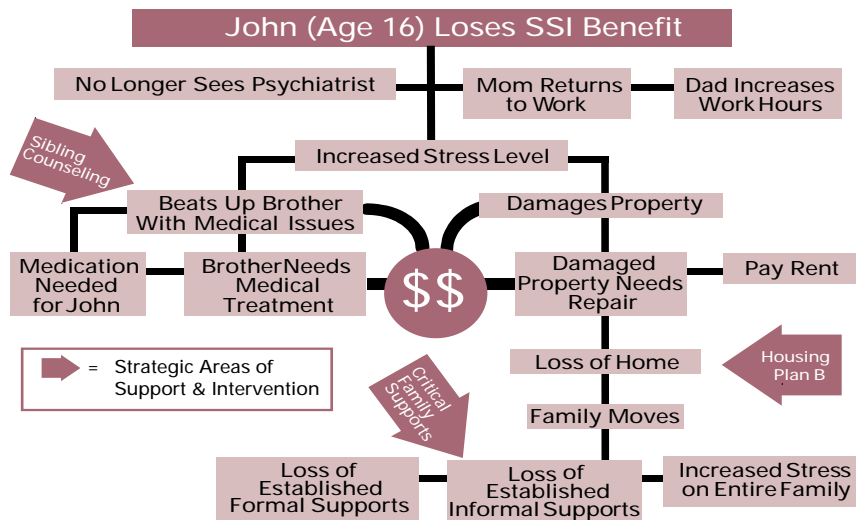
“I had a certificate to try and find a house. Being able to pay our motel stay was coming to an end. I knew that I had to provide for the kids, and I asked some people, down here to take care of them. I still had the youngest child with me, thinking that I could find a friend that I could stay with, just with one child and not four. One of the ladies that was watching [my daughter] thought that it was completely inappropriate and called [Human Services], and said that I had basically abandoned them. The court agreed with that...and my kids went to foster care.”

When talking about the impact of the loss of SSI on her daughter and the rest of the family, one parent was fairly direct about the fact that not having extra money really did shake the already fragile stability that her family had previously.

“The obvious things are that we did become homeless and our family tore apart...I think it’s all pretty well connected.”

Changes in the SSI benefit policy affected multiple dimensions of the families’ lives that went beyond the obvious financial ramifications, creating a *cascade effect* which resulted in negative changes in the families’ quality of life.

Cascade Effect



For John and his family, the loss of the SSI cash benefit resulted in the loss of overall household income. When John lost his SSI, he no longer saw his psychiatrist (although he actually remained eligible, the family was told he no longer qualified), his mother returned to work and his father increased his hours at work, thus reducing the time they could spend with John. The family reported that this led to increased stress for the whole family. John’s behavior worsened—in one incident, punching holes in the walls of the family’s rented home and beating up his brother, breaking his arm. John’s father explained that he then had to decide what to pay for with his limited “pot of money”—repairing the damaged property, getting John’s brother medical attention, getting John’s medication to help control his behavior (which ceased after he stopped seeing the psychiatrist), or paying the rent. He felt there really was no choice but to pay for John’s brother’s broken arm. The family lost their home and they had to move. As a result, the family reports they lost the support of their neighbors and family that lived near by. They also lost their established formal support system, one being the children’s doctors. And, there was an increase of stress on the entire family as a result of the move.

FINDING 11: Most families experienced increased levels of stress from the changes in SSI eligibility and the review process.

Families suffered constant stress from the loss of benefits or from having to wait for the outcome of their appeals. Loss of benefits was a contributing factor in other problems, including the loss of one child to foster care, concerns about siblings losing SSI, loss of Medicaid and escalations in behavioral problems.

“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, you get to the point that you want to give up.”

In coping with the loss of benefits, a few families sought to obtain welfare benefits for their children. Others were taking steps to replace lost income through budgeting or obtaining employment. Those who obtained employment reported that they had less time to spend with their children. One mother believed her children were at greater risk for health problems because she had returned to work. She was no longer home to ensure that they received their medication for cystic fibrosis. In another family, a sibling quit school to go to work and help support the family. Other families were forced to face untenable choices, such as borrowing money from or living with extended family.

“Sometimes I sit back and look at the bills that can’t be paid and wonder when they’re going to come and take the car.”

“I pay half the bills. Let’s say that I get a bill for \$50, I pay half of it. In summer, because of the heat, electric bills were up to \$180. In December, I couldn’t pay and they interrupted the electricity supply. It lasted for 24 hours, until I could borrow money and pay. If I pay bills in their entirety, I cannot buy food.”

Near the end of the study, families continued to worry about the status of their benefits and the potential financial impact. This constant worry caused a great deal of stress and emotional strain. Those families that had lost benefits restructured their finances, tightened their budgets, and some considered divorce to become eligible for TANF (AFDC).³ Children became impatient and angry at being denied activities, material goods, and time with their parents. Although discouraged, families were taking necessary action to cope with their circumstances. In general, finances were tighter and parents had to be creative to meet the needs of the family.

“And, wondering what all bills we can get paid. It’s puttin’ us in a real bind. It really has. And a \$5,000 funeral expense on top of all that [for father-in-law], . . . and the groceries bein’ as high, we get no AFDC and we get no food stamps, everything is bought with cash. So yeah, it puts us in a bind.”

³ TANF (Temporary Assistance for Needy Families) is the federal government’s primary welfare program replacing Aid to Families with Dependent Children (AFDC) with the Welfare Reform legislation in August 1996.

“SSIs just kind of a back up I feel that needs to be there for him. I hope. I hope I don’t get another letter in the mail or something. There’s always that in the back of my mind that someday they’ll probably cut him off. But as long as he could keep the medical card, I would be happy.”

“It hurt. They don’t allow you to go out and get a second job because if you do then you lose all benefits. I need the extra income to make a living. But I need his medical. If I don’t have that then I can’t afford a psychiatrist and medications on my own. Even getting him on mine it would be more for me to pay medical and everything else.”

“Well, I’m trying to do the things the same way as before, as I am able to. I am trying to stretch the money to last the entire month. You have to pay rent with the money from Welfare because if you don’t have to pay rent and you take money out, they give you less money.”

FINDING 12: Continuity of mental health care was disrupted for many families, especially those without formal supports.

“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.”

Many families experienced an impact on their ability to access services. Florida families experienced the greatest impact on service access, with 8 in 15 reporting that services for their children were discontinued or no longer an option. These included visits to therapists, doctors, medication, and special school programs. In contrast, only two Kansas and two New York families experienced a disruption or discontinuation of therapeutic or other mental health services, with three being temporarily without a medical card. One mother in Kansas commented that the loss of benefits left her without support and validation to convince the school that her child was disabled.

“I would never have moved if I knew they were going to cut me off or considered him not disabled because I cannot afford therapy for him. Besides that, I can’t get Medicaid, because I make too much on my job. So when they cut me off, I no longer get the Medicaid for him to get the therapy.”

“I have to be, you know, get real skimpy with his medicine. We’re trying to stretch it out.”

FINDING 13: Families experienced a loss of ability to provide “normalizing” supports.

The loss of benefits typically impacted children’s recreational opportunities, including their ability to participate in various activities, including sports and school outings. Parents were also less able to provide for their children in terms of clothing, school supplies, and quality food. Children received less during the holidays, with parents feeling that their children deserved more than they could afford to give.

“Well it (the SSI cash benefit) improved the kids’ standard of living. I was able to buy her some clothes and put ‘em through school, get the school supplies they needed, where before they didn’t have the clothes that they needed and we couldn’t half the time get their school supplies. We just didn’t have the money.”

“I know his attitude has gotten worse. There isn’t any money so yeah, you could say there is an impact on them money-wise, cause they want to do things and I am just barely keeping my head above water. There is no money for them to do anything with. I mean I doubt whether or not seriously they will even have a Christmas.”

Despite the financial impact on the families as a whole, parents often sheltered their children from the process, keeping them from recognizing a direct impact. However, a few children were aware of the change and had difficulty understanding why they could no longer do certain things, becoming stressed, depressed, or angry. The impact of the SSI changes on the families’ quality of life cannot be overstated.

“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.”

“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 don’t have no money for some of our bills so therefore there can’t be no 4th of July. They’re very understanding, but I know that it hurts them because last year they was able to get fireworks and stuff. This year I don’t even have enough money to pay all the bills.”

“It’s a shame to say it ‘cause it’s summer and the kids were having high hopes on, you know, some kind of summer. But they’re just going to have to deal with it until something breaks here.”

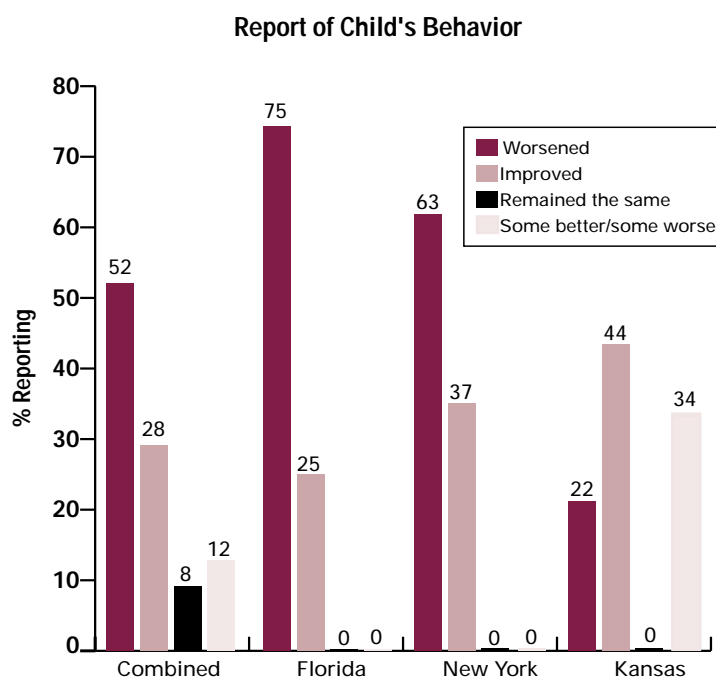
“By them cutting this off, they really put me in a hole. Cannot get the proper food, because being that he is at the age he is, he eats a lot of vegetables, meat, you know, stuff like that. I cannot afford it, I can’t.”

FINDING 14: While about half the families reported that their child’s behavior had worsened over the course of the study, there was a pervasive increase in parental anxiety about their child’s behavior in school, at home, and in the community.

Some parents feared that the loss of cash benefits would promote their child’s involvement in illegal activities. Without pocket money to spend and diminished access to recreational interests, there was an expectation that children would get into trouble. In general, parents reported their children’s stress had increased as recreational outlets had

decreased. This was especially true among older children, who reportedly demonstrated increased behavioral problems. In New York, one child's grades dropped after his mother could no longer afford his transportation (bus pass) to and from school, causing him to endure a very long walk. Another missed school because of SSA appointments.

A few families reported that although the child seemed to be doing better at home, their grades and behaviors at school had become worse.



Overall, 52% of the families reported that their child's behavior had worsened over the study period, with 28% reporting that their child's behavior had improved, 8% reporting it had remained the same, and 12% reporting their child's behavior was some better and some worse. A closer look by site revealed that in Kansas (where all families were served by the CMHS site KanFocus), 44% of the families reported their child's behavior was better, 34% some better/some worse, and 22% worse. In New York, 37% of the families reported their child's behavior was better and 63% worse. And, in Florida, 75% of the families reported their child's behavior was worse and 25% reported their child's behavior was better.

FINDING 15: Few families changed residences during the course of the study.

While a few families did change residences over the course of the study, most did not—and those that did, did not do so for purposes of accessing better benefits or services. The reality is that most families could not afford to move and/or had informal and formal support systems they did not want to leave.

“Well, since we own our house and I don't want to ever move again, this is where I'm going to be unless they cut my phone number.”

One family in Kansas moved repeatedly due to a variety of financial problems, while another moved to another town at the end of the study after her son was sexually molested by a neighbor. In Florida, two families moved to a better or larger home and two moved for the purpose of decreasing their rent payment. In New York, a few families chose to move to be closer to family.

"I wasn't able to pay my light bill over there on Walnut Street. I stayed with Tracy's father for a week and I stayed in a motel for a couple of weeks in Lawrence, Kansas. Then I came back to Pittsburgh with a friend ..."

FINDING 16: While a few families that lost benefits reported some positive outcomes, those families that retained the benefits reported having greater peace of mind, primarily due to the assurance that their child had medical coverage.

Families that lost benefits reported improving their financial management skills, with some children learning greater financial responsibility. Some parents were sharing their financial struggles with the children. One reported that this communication was helping to build trust, and strengthen the bond between parent and child. In one family, the loss of SSI cash benefits income allowed a sibling to become eligible for Medicaid through TANF (AFDC). The loss of benefits for a mother in New York resulted in her enrollment in an AIDS case management program, which ultimately provided a great deal of help.

"It made me grow up a lot. Understanding that it wasn't going to be there forever. I've got a good job and good insurance. So, in a way, maybe it did help, but it hurt too. We miss it. I wish we were still getting it, for a little while anyway."

"Things are positive because he is on medication which he does need. He's getting to see a psychiatrist which he does need. And we're able to do what we're able to do just to go meet with people, stuff like that."

"It paid some bills. It paid for some Christmas stuff and I got it around December the \$2000. I paid more on payments of stuff instead of minimum, so that helped a lot."

"A lot better off in some senses 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."

"Oh well, I was behind in rent. Now I'm trying to catch up on my rent by paying the landlord \$200 the first of every month. . . now (with AIDS case management) I can do more for the kids, I can buy more things for them, that I couldn't have did before when it (SSI check) had stopped."

When reporting positive outcomes, only those families in Kansas that had *stopped receiving SSI cash benefits* found peace of mind because they reasoned that it meant they no longer had to continue in the process of appeals. Florida families tended to base a "positive outlook" on the continuation of benefits and the receipt of necessary care and medication for their children. Kansas and New York were the two sites in which some primary caregivers reported learning about the system, their personal rights within the system, and how to be better advocates for their children.

Findings Related to Medicaid and Health Care Coverage

FINDING 17: The main reason most families appealed was the potential loss of Medicaid.

In the initial interviews, the majority of families reported that their children were covered under Medicaid. Florida represented the exception, with only six in 15 children having coverage. These parents reported that Medicaid had been discontinued when their child was determined ineligible for benefits. In addition, many of the families that had lost benefits had to obtain Medicaid coverage for their children through public assistance (TANF). In all three states, some of the families that lost Medicaid when benefits were denied and were not eligible for Medicaid through TANF (AFDC) due to their income, pursued coverage for their children through programs offered through the state or county government.

Future interviews revealed that in some cases the status of children's Medicaid coverage was uncertain. Of those families in Kansas receiving coverage through the state, several reported that the coverage was limited, failing to pay for dental care or cover the cost of eyeglasses. In the face of these limitations, a few parents delayed needed care for their children. When the program was redesigned, the coverage was reportedly very comprehensive. In general, variability in the type and continuity of insurance coverage had an impact on the care children received. One parent reported struggling to purchase psychiatric medication for her child, being forced to "stretch" it over the course of the month to make it last longer.

Throughout the course of the study, there was some readjusting of coverage between private insurance and Medicaid for a few families in New York. When Medicaid was interrupted for one family during the reevaluation, the child received medical vouchers through a community program. One child had no medical coverage through the majority of the study, while in another case the child's siblings were not insured.

At the time of the final interview, six of the 10 remaining families in the study in Kansas had children covered under Medicaid, two through private insurance, and two through Health Wave.⁴ In Florida, six families were still receiving Medicaid, two had private insurance, while another was part of a "share costs"⁵ program. In New York, most of the children were covered under Medicaid. One child was uninsured and two children were covered under private insurance.

⁴ Health Wave is Kansas' version of the Children's Health Services Insurance Program which began January 1999 and extends health insurance coverage to uninsured children whose families earn too much to qualify for Medicaid and too little to afford commercial health insurance.

⁵ Share costs programs allow families that exceed the income limits of Medicaid to receive health insurance benefits by making co-payments.

The Fact

Ex parte re-determination

When a child loses SSI (or other cash assistance, such as TANF) for any reason, the state may not terminate Medicaid until it has made its own re-determination of whether the child is eligible for Medicaid under any alternative category (such as child under the poverty level). The state may request additional information from the individual, but may not combine a request for information with a termination notice. The state also may not say that the child must reapply to retain Medicaid. Notices that say that Medicaid benefits terminate automatically because the state has been told that SSI has stopped are illegal.

Center on Budget and Policy Priorities

The Fact

Continuing Medicaid benefits during SSA appeal process

If SSI has been lost because the child no longer meets the definition of disability, the state may not terminate benefits for sixty days—the time the child has to appeal the SSI termination. If the child appeals, Medicaid must continue throughout the appeal process, through the SSA Appeals Council.

Center on Budget and Policy Priorities

FINDING 18: 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.

The Fact

Special Rules for Children who were receiving SSI on August 22, 1996

Under the Balanced Budget Act: No child who was receiving SSI on August 22, 1996 should lose Medicaid solely because they have lost SSI under the new disability standards imposed by Congress under the welfare law. This is because these children remain eligible for Medicaid under the old SSI disability standard (rules set out in directives from the HCFA Medicaid Director to state Medicaid Directors dated February 6 and April 22, 1997).

Center on Budget and Policy Priorities

“They said ‘any time you have an emergency, go to the emergency room’. But now what they are doing, they are giving me forty visits a year, and when he runs out of that you get extended for ten more visits (you take it to the doctor and the doctor fills it out). That’s all you can do.”

“And then Medicaid is cut off and the insurance company, from my personal experience also when I was working my insurance company, wouldn’t carry my son. They would not carry my son even though it was cerebral palsy. They would not carry him because of the cerebral palsy.”

“It started out with a toothache, so I went to the dentist. Then I got an earache. Then I got a cold. I just got really sick for a good month. . . As a matter of fact, I’ve been sick for this past month because I haven’t been able to go to the doctor. We usually go to get check-ups once a year, but I had to use all the money in the move.”

When faced with a medical problem, many of the primary caregivers in the study were “self-pay.” This caused them to avoid seeking primary or preventive medical care; instead families waited until the crisis was 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.”

In a few cases, special arrangements were made to ensure continuity of care for parents. One physician in Kansas agreed to charge one mother only \$5.00 per office visit, to motivate her to receive follow-up-care for high blood pressure.

“I tell him [the doctor] I don’t have insurance and he gives me samples and stuff. He’s a real good doctor. If he’s [son] sick or something, I’ll take him there. So that’s \$30. He’s a really good doctor.”

Another mother received care from the free clinic or through the county health department. However, due to limitations in the services offered at the free clinic, this mother had put off follow up care after recovering from cervical cancer. Others were covered under Medicare and/or had supplemental insurance. A few families in the three sites had private health insurance or were covered under Medicaid through TANF (AFDC).

“... we make too much money. When you go out for Medicaid they don’t take into account what your out-go for medicines is. It’s strictly off what you make. And it’s not your bring home pay. It’s your gross. And we have the insurance comin’ out of his checks, never mind the several hundred dollars a month in medicine that out-go. They just tell you that’s tough.”

“Because July 1st he’ll have insurance. Now his is cheaper than even mine, so I cancelled my Cobra and I’m going on his. Tim’s going on his too, because I don’t know if SSI is going to pan out. We have a hearing this month.”

Findings Regarding Coping Mechanisms of Families

FINDING 19: Parents and primary caregivers were not passive in response to the loss of SSI. They made lots of decisions weighing costs and benefits.

Families made a variety of key decisions throughout the course of the study, including how to respond to the review and denial of benefits, and if and where to seek help. In Kansas, most made the decision to make at least one appeal based on their child's need and the family's financial need, with some being encouraged by family, friends, mental health staff, schools, and attorneys to appeal. After losing one appeal, a few primary caregivers decided against further appeals, preferring to secure employment to replace the lost income. In weighing the pursuit of multiple appeals, parents took into consideration the child's need, time away from work, and the likelihood that they would prevail. Those who decided against second and third appeals frequently commented that they did not believe they would prevail or did not want to endure the stress of further appeals. Rather, they chose to accept and cope with the decision. While some had resigned themselves to the original determination, a few families in Kansas were under the impression that to mount a third appeal required the assistance of an attorney. As they were unable to afford an attorney, they did not pursue further appeals. The few who sought the assistance of an attorney believed that they needed help with their appeal or that having an attorney might put pressure on the SSA to expedite the process or make a favorable determination.

After losing the benefits, families made decisions and choices to ensure that the basic needs of the child and family were met. In order to avoid moving, one mother in Kansas approached her landlord to have their rental home HUD certified, thereby lowering the rent. Several applied for Medicaid for their children through AFDC (TANF), with a few receiving health coverage through state sponsored programs. In one Florida family, the parents had divorced in order to become eligible for Medicaid when they lived in another state and were now deciding if they would need to divorce again.

"I was told Medicaid would pay for his prescriptions, but I was told he wasn't on the list when I called. So, I pay out of my pocket, because I'm afraid that if I keep calling to find out, my son won't be able to keep getting his therapy that he needs."

Other families reevaluated and reworked their household budgets. Primary caregivers and/or their significant others made decisions to return to work, take a second job, work longer hours, or otherwise compensate for the lost income. One mother decided to pursue child support more aggressively, another returned to work to be able to afford child care.

Families were also making decisions that did not have a direct bearing on the SSI benefits, such as child custody issues, responding to child molestation, moving and medication issues. Others were making decisions about their child's education and school placement.

After losing the benefits, families not only had to decide whether to appeal, seek help (e.g., legal, child support services, etc.), and determine next steps to take in the SSI process, but families also made decisions and choices to ensure that the basic needs of the child and family were met.

“Nothing. I just gave up. I can’t handle the stress no more; I just don’t want to do it no more. That’s the whole idea of doing it, they wear you down to where you just don’t want to do it no more.”

“I’ve decided I can’t move to Florida even though the accident [mother’s boyfriend] and getting hopefully a settlement for his injuries is very important and could be a wonderful major thing for me and my kids too. I need the support of help with the kids that I’m getting here in Pittsburgh, Kansas. I have thought about going out there with him, and I said to him, ‘I have to be where I can have help with me.’”

“I just gave up on that. They just send you a letter saying whether you’re denied or approved and so when I started working, I just gave up on that, because they take their time in doing what they’re doing and I hate to tell them all my business. Then you have to bring in all these papers to prove what you’re saying is true or not true. I said forget it!”

“I didn’t ask for help. I went to Welfare, and they gave me a letter there, I don’t know if I lost that letter. I applied for him, and then I returned two checks, but then I cut him from welfare because they said he couldn’t continue to receive checks, so I cut him from welfare. So I said, ‘let’s wait to see what happens.’ And they are still giving him checks.”

“I’ve been appealing every time they send me a notice stating that he’s going to be cut off I appeal. 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.”

FINDING 20: Families became better navigators of public supports.

In New York and Kansas, mothers reported gaining an education of the inner workings of the benefit system, as well as the resources offered by the mental health system. They increased their understanding of their rights and the rights of their children. Based on this increase in knowledge, they felt more capable of advocating for their children, which in some cases translated into improved self-esteem and a greater sense of competence as a mother.

“The benefit is that I’ve learned to communicate with my son’s doctors and I’ve learned to keep receipts because you feel you don’t know when they’re gonna call you into an interview again, and you have to keep everything updated.”

One mother credited the legislated review with prompting her to submit her son for psychiatric reevaluation. Based on this reevaluation, the son received a more comprehensive and accurate diagnosis. Armed with this information, the mother felt better equipped to help her son. Similarly, in preparing for the appeal, another mother requested and received a letter of support from her son's psychiatrist that validated the severity of her son's disability.

FINDING 21: Other insights were gained by the family, which confirmed their own strengths and validated their resiliency.

For many of these families, the changes in SSI and outcomes were viewed as one more crisis to deal with. As noted in an earlier finding, the health challenges faced by families were great. While the medical difficulties persisted, families continued the battle.

“Yes, that’s [poor health] just one of those things. I’ve had bad luck all my life when it comes to health. I’m a fighter. I don’t give up.”

In families where benefits were lost, a few of the mothers reported becoming more self-sufficient and independent. One of these mothers reported an increased sense of self-worth when she returned to work to make up for losing the SSI cash benefits. Her ability to contribute financially to her family gave her an increased sense of value. Another mother recognized her own ability to cope with stressful situations and realized that “nothing is forever.” In Florida, one mother reported that going through the review and appeal process reminded her that she was a “fighter.” A few families reported gaining what they considered were important insights, such as realizing that time spent with their children is more important than money and gifts. Others reported developing closer family relationships as they had to pull together, with interactions improving or becoming deeper. Initial reaction to potential loss of benefits often resulted in increased attention to financial planning and increased planning for future vocational or educational activities to increase employability.

“I’m getting really educated. I mean I feel like I’ve become a stronger advocate for special needs children. I mean, you know, it’s been a real learning experience and it’s made me more vocal. ‘Cause before I probably wouldn’t have said anything. But now these things are... I think it’s shown me it’s very important. Because [child’s] dad had problems. He was dyslexic, he had problems with school. You know, these things could be hereditary. So it’s not just for [child] that I want a voice and help out all I can, it’s for all the kids because without them we’re not going to have much of a tomorrow.”

“I guess I have been such a fighter all my life that I know that if I do lose it, we are not going to be dead. I will find some way of bringing it up and trying to get us back on our feet where we can do things.”

While there were few changes in the primary caregiver's education over the course of the study, a few were pursuing educational opportunities in response to the SSI review and changes in eligibility. One of the mothers who had completed high school returned to adult education classes to learn basic skills. Even though she had graduated from high school, she could not read. After confiding to a friend that she could not read to her children, the friend urged her to pursue adult education classes. Another mother was attending interior design school, while yet another was enrolled in vocational rehabilitation classes.

“Now I have to..., I'm going to this adult education thing. It's like where you can get your GED and stuff. But see, I already have a high school diploma. But when I graduated from high school, all I could do was write my name. I feel like the school system let me down and I will not let my kids down with this (loss of SSI) happening.”

“I'm going back to school, now. We're taking on social work. Well, I'm taking on social work. It's really like introductory classes right now. I'm beginning all over again. It's been years, so it's basically like introduction. But I have to do it to get ahead.”

FINDING 22: Informal and formal helpers were major sources of support; however, support from some informal and formal sources was inconsistently provided.

Families in Kansas reported receiving support from friends and family, with several having the support of their child's case manager. Those in New York involved with F.R.I.E.N.D.S. often had the support of a case manager. Other supports included parent advocates, churches, school counselors/psychologists, and a parent support group associated with mental health in Kansas called Keys for Networking. In both Kansas and New York, physicians and therapists, along with social workers and other school personnel were also periodically available to assist with the review and/or appeal. At both sites, several children were receiving mental health services, including psychiatric care, therapy, and after school therapeutic recreational programs. A few families received some help from the SSA office, an attorney, churches, co-workers, or employers. One mother retained an attorney to help her with the review and appeal after being accused of “coaching” her child to say certain things during the medical assessment. This same mother reported that she did not receive the letter of review until after her child's benefits were cut off.

Throughout the course of the interviews, families, friends, case managers, local community centers and advocacy groups emerged as providing the most consistent support in Kansas and New York. These sources provided moral, financial, and emotional support, as well as offering daily assistance with things like childcare and transportation. Special education teachers, attendant care staff and other paid supports were also very helpful. One parent reported enrolling with her sons in the family swim program at the YMCA. Others attended substance abuse groups and victim's advocacy groups.

In contrast, supports and resources were very limited for Florida families. While most parents in Florida felt they had very few supports, they periodically mentioned friends, significant others, and neighbors as providing moral support and helping out with daily needs, including transportation. Extended family was the primary resource, providing childcare, provide emotional support, and some financial assistance. A few families mentioned churches as being supportive with childcare and emergencies. One family mentioned a supportive pediatrician, while four indicated their child was seeing a therapist. Only two families had case managers. Another turned to the American Heart Association for support. One mother appealed to a Congressman and a Senator for help with her SSI appeal. Attorneys, vocational rehabilitation specialists, physicians, and tutors also represented important supports for a few families. Others received support from the Center for Women or the Boys and Girls Club. Emergency help was also received from St. Vincent De Paul and the Salvation Army. One child was enrolled in an after school program which gave him a recreational outlet. Although formal supports in Florida were reportedly limited throughout most of the study, 10 of 15 families reported having some form of support from family and friends at the end of the study.

It appears that one of the major differences among the sites was the amount of supports utilized by families during the study period. Most supports were reported to be used in Kansas, at the KanFocus Children's Mental Health Services (CMHS) grant site.

"You know, [friend] and I have been friends for 10 years and she's a great friend. I mean she's like a sister to me. When I get depressed, she's there. When I need someone to talk to, she's there. You know, because she's on the same thing with her little girl. You know, so we try to help each other out..."

"Keys for Networking works with special needs kids and their families...like negotiators kind of. And when you have everybody that's so mad at everybody that you can't sit there and talk, then these people came down from Topeka and they did what they call a wraparound. They worked with the school, with mental health, they worked with me."

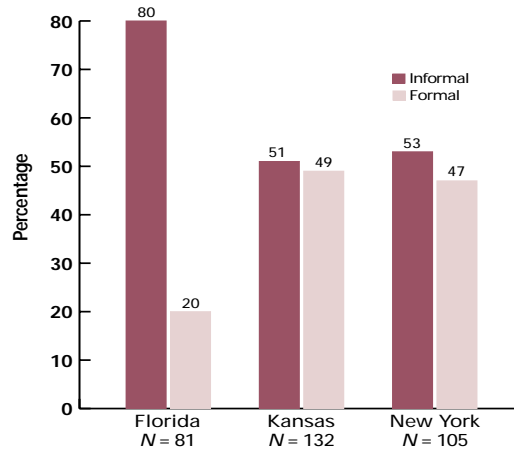
"They've all been supportive. You know as far as mental support. The therapist lets me go in and talk to him once a month. It's getting harder and harder to see the therapist. He's overbooked."

"...they keep me from losing my mind. They keep encouraging me. In fact I made friends with one of the girls in church and she's really nice, her little girl is P's age and they come over they play...and she's between my age and my son's, and he really likes her and she tries to draw him into conversation and get him to open up a little bit. It's minimal support in that area."

"He sees a counselor at school now. He sees a counselor on the property over there on the campus. He sees him I guess once a week. We see him also once a week, Thursdays. Parents have to go too."

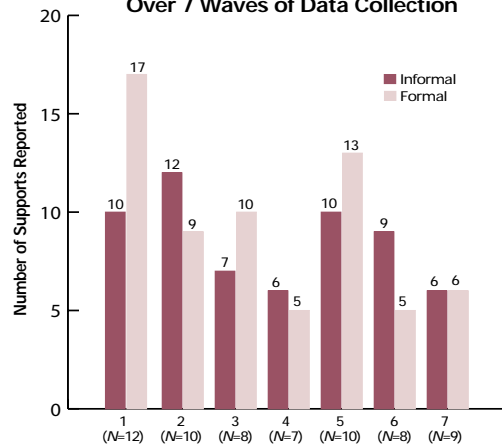
Families in Kansas, who were served by the CMHS site reported the most frequent use of formal and informal supports (A total of 132). Florida, a non-CMHS grant site, reported the highest percentage of informal supports and the lowest percentage of formal supports of all the supports used.

Formal and Informal Support Reported



For families in Kansas, the mix of support from the informal and formal supports proved to be very helpful. Upon closer examination of the entire group of families over the 7 waves of data collection, it appears that families made an effort to draw on informal supports when formal supports declined and vice-a-versa.

Kansas Sources of Formal and Informal Support Reported Over 7 Waves of Data Collection



“And St. Vincent de Paul, I went to them... They bought me a Thanksgiving dinner this year...a turkey and everything. They brought it Monday I think... They came with food for me...besides things...a turkey and everything. They helped me two months ago on my rent, cause I didn't have all the money. So I had to go to the St. Patrick's church and they deal with St. Vincent de Paul and they had to come to my house and, they helped me with my rent...not in November...but October's rent.”

Formal supports were also sought outside of the SSI process. One of the most frequently mentioned supports was educational. Parents were making efforts to help their children be successful in school by obtaining tutors, enrolling them in special programs, and looking into vocational/technical school. Despite these efforts, most children continued to struggle behaviorally and academically, experiencing poor grades and ongoing behavioral problems.

The findings suggest that the support, whether it was from a friend, family member, or professional service provider was not always consistently offered, available, or requested. Over the course of the study, factors influencing help seeking became more apparent. What also became clear through the longitudinal nature of the study was that informal supports run out of resources themselves and cannot always be counted on. Families expressed concern about “overusing” informal supports. They would be attentive to the amount of time, transportation, child care or money a particular resource provided and refrain from asking for awhile or stop asking altogether if they felt it was becoming difficult for that resource to continue providing support. Some families expressed fear at seeking formal supports, afraid they might ‘lose’ their child to child welfare if a worker saw the living condition of the family.

“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.”

“Maybe because I watch too much TV...but I’m scared to tell anybody what’s going on, because I’m scared [Human Services] is going to get involved.”

Findings About the SSI Process

FINDING 23: Families were taken by surprise and distressed when notified that their child’s eligibility for SSI was going to be reviewed.

“It was like, how am I going to pay my bills now? It was like, oh no, I’m struggling now. What am I going to do? You know it was bad.”

“Sad, sad. I thought it was terrible because I knew I wasn’t going to be able to pay any more doctor’s bills. Or send him to any more counseling or anything, because that’s it. I mean there’s no income to do it...I don’t have any insurance for him.”

Across sites, families reacted to the notification of review with anger. They also expressed feelings of helplessness or perceived the review as being unfair. Parents feared losing the benefits and how that would affect their finances and their child’s Medicaid coverage. They also reported they were tired of having to deal with the uncertainty of the system. This notification caused stress and feelings of depression for some, while a few indicated that they were resigned to losing the benefits.

“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.”

“I was like in shock. They bring SSI all these years. Why are they gonna stop it now? Aint nothings changed. They (her children) are still in special education. They are still slow. So why they stop it?”

“I see people that seem normal and they still get SSI and they are not taking medicines or anything. I have to give medicines so that he can control himself in the classroom.”

FINDING 24: 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.

After receiving notice that they no longer qualified, families had 60 days to appeal. They had to file appeals in the first 10 days if they wanted to continue receiving checks while they waited for hearings. The benefits the family received during the appeals were considered an “overpayment” if they lost after all the appeals. However, families who could show that they appealed the denial of SSI benefits “on good faith” did not have to repay these benefits. According to the SSA, more than half of the families that appealed prevailed.

Families in all sites were in various stages of the process, either awaiting the outcome of their appeal, mounting a second or third, or being notified of the outcome of their review or appeal(s). Not appealing was not passive on the part of these families. Many families made a conscious decision not to appeal because of the risk associated with paying SSI cash benefits back to SSA should their appeal fail. Families reported being encouraged by friends and family to appeal, while being discouraged by SSA staff or other formal service workers from appealing on the premise that their child would not qualify in the redetermination process.

“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.”

“I called them [SSA] and they told me that if I wanna get help, I should talk with Legal Aid... and then I called Legal Aid and they told me I’d have to call this number; it’s in Kansas City and the lady she’s really nice and she gave me an interview over the phone, and she said, ‘let me know what happens.’”

A few families that sought legal help with the appeal process ran into problems of accessing help from the “free legal assistance” services they were referred to. They reported that they never spoke to the same person or no one returned their calls.

“I did a first appeal. I could’ve [appealed again], but I’d have had to probably get a lawyer I think and all that stuff, and I can’t afford that.”

FINDING 25: Upon filing an appeal, all families were faced with a choice of whether or not to continue receiving the SSI cash benefits during their appeal, with the understanding that they would have to repay the benefits if they lost the appeal.

“And that letter makes you feel like it’s just over with. But they say, at the end, they say, ‘if you want to appeal this, you can’...so I did.”

The few families who chose to continue receiving the benefits during their appeal process lost their appeals. They then received letters from the SSA instructing them to repay the money, which they responded to with shock and fear. All but one parent applied for and received a waiver. The mother who was in the process of paying back the money never mentioned a waiver and therefore is assumed not to have known the option was available.

Only four families out of twelve in Kansas and three out of five in New York elected to receive benefits, fearing that their appeal would be denied and they would be responsible for repaying money to the SSA. In contrast, most of the families in Florida retained their cash benefits during the appeal process. Also in Florida, a few families who had already been denied an appeal had received letters instructing them to repay benefits.

“They sent me this letter saying that I owed \$5,000. I tried to waive it but I couldn’t...I went to court, I tried to waive it. I called and they said I couldn’t. I had to come into the office.”

Over the course of follow-up interviews in the third and sixth months of data collection, a few families in Kansas had made a decision not to pursue the benefits further, based on the denial of one or two appeals. In all sites, the families who had continued to receive benefits during appeal were instructed by the SSA to repay those benefits. As this represented a serious financial burden, they applied for and received good faith waivers, with few exceptions. Others were struggling with fluctuations in their benefit amount, which varied according to monthly income. In a few cases, overpayments resulted in a temporary loss of cash benefits.

“And in the waiver it said if you don’t agree with us, tell us why you think you don’t have to pay the money back. I told them I was going to be unemployed and all that and I just figured, oh, maybe they’ll just not make me pay it back for a little while...and then I got a letter the other day and it said they just decided that I’m not going to have to pay any of it back.”

“Yeah they did [asked her to pay it back]. But I told them, you know, that it had been spent on bills and for [child’s] needs and I asked for a waiver and they waived it.”

A closer examination of the differences between families across sites revealed that unlike families in Florida and New York, several families in Kansas had no appeals pending throughout the course of the study. These were families who had been denied benefits based on one or two previous appeals, and ruled out further appeals or reapplication, convinced that future outcomes would again be negative. Those facing a third appeal were under the impression that they needed an attor-

ney to continue with the process. Because they lacked the funds to hire an attorney and did not believe the outcome would change, they accepted the denial. At the same time, the few families that won their appeal in Kansas or had benefits reinstated through reapplication were receiving back pay from the SSA. This money constituted benefits that had been withheld during the appeal. Three families in Florida had elected not to appeal, while others were already mounting a second appeal after being denied the first time.

“Well, at first I kind’a just accepted it because I thought, well maybe there’s just...and I heard they were doing this to everybody and then I thought, no, no. So I finally went to appeal.”

For the purposes of analysis, an algorithm was devised to classify families by their receipt of SSI cash benefits over the course of the study. This description and analysis included only those families that completed all of the interviews.⁶

Overall, this classification system clearly differentiates families in Kansas from those in Florida and New York, based on receipt of SSI cash benefits. While most of the families in Kansas were classified as type C, indicating that they *were not receiving* cash benefits throughout the study and *were not receiving* benefits at the end of the study, those in New York and Florida were classified as type B, indicating that they *were receiving* benefits throughout most or all of the study and *were receiving* benefits at the end of the study.

Only two families (one in New York and one in Kansas) were classified as type A. These families *were receiving* cash benefits throughout the course of the study, but *were not receiving* these benefits at the end of the study. Only one family (in Florida) was Type D. This family *was not receiving* the cash benefits throughout the course of the study and *was not receiving* them at the end of the study.⁷

| SSI Type Analysis (Includes only families that completed all phases of study) | | | |
|--|------------|------------|------------|
| Family Type | New York | Kansas | Florida |
| A. Received money throughout most or all of study. Did not receive money at the end of the study. | 1 family | 1 family | 0 families |
| B. Received money throughout most or all of the study. Received money at the end of the study. | 6 families | 1 family | 5 families |
| C. Did not receive money throughout most or all of study. Did not receive money at the end of the study. | 1 family | 6 families | 2 families |
| D. Did not receive money throughout most or all of study. Received money at the end of the study. | 0 families | 0 families | 1 family |

⁶ Due to the small size of the sample, the ability to generalize this analysis to families beyond this study is limited.

⁷ Areas in which differences emerged among families based on family type include appeals, Medicaid receipt, impact on child, and reporting positive outcomes. Analyses of the data using family type failed to differentiate families either within or across sites on several other topics of study. They include: Co-occurring events, Impact on Family, Reaction to the initial review/experience with review process, Experience with the appeal process or the SSA, Experience of support, Primary caregiver educational level, Child education, Family living situation, Primary caregiver employment, Child diagnosis and behavior, Use of SSI cash benefits, Primary caregiver or family health, Child health. New York data were unavailable based on family type on the following topics: Co-Occurring Events, Support, Decision Making, Reaction to/Experience with Initial Review, Living Situation, PCG Employment. Florida data based on family type were unavailable on Impact on family.

Differentiation based on family type did emerge in the appeal area. When considering whether to appeal, a few themes appeared to differentiate families in Kansas and Florida. Among Florida's type B families (*those who were receiving SSI cash benefits for the child throughout most or all of the study and were receiving those benefits at the end of the study*), the primary factor in the decision to appeal was the child's need for the benefits or the family needed the income. In addition, the decision to seek employment in these families was typically based on the possible loss of SSI benefits. In Kansas, all families made similar decisions regarding their SSI benefits. Some families opted not to appeal initially, only to reverse their decision later based on a change in their child's diagnosis or in their employment income.

FINDING 26: Families found the SSI review process difficult and confusing.

The review process itself was described as complicated, involving a great deal of paperwork and many procedures. Those families who were denied benefits on appeal described the system as difficult to navigate and reported feelings of betrayal, confusion and depression. The process itself was stressful and exhausting.

Throughout the process, families felt scared and upset, with a few in New York believing that they were being persecuted by the SSA. There was also some dissatisfaction with how the medical evaluation was conducted.

During the course of the study, several families had difficulty describing the process they went through to retain the benefits. Whether they were successful or unsuccessful, they expressed confusion concerning the outcome. Other parents were able to recount the appeal process, describing physician evaluations and their participation in hearings. Families were also confused concerning the difference between the legislated review and what they referred to as "re-certification." This re-certification was apparently a scheduled annual or biannual review of the child's eligibility for benefits. Given that these reviews were similar, it was sometimes difficult to determine which process the families were talking about. There was also a contrast in knowledge and ability to deal with the requirements of the review. One parent did not understand the review, while another immediately sought public assistance and help from the legal system and the schools. At the end of the study, families reflected on the review as causing "frustration" and disappointment, along with some "confusion" and "discouragement."

In New York, some families expressed a lack of concern about the potential loss of benefits, while others were very concerned. Several expressed confusion about the purpose of the review and the reason their child's benefits were at risk. In response to the notification of review or the denial of benefits, some families contacted the SSA to find out more about the review or the results. There was also some confusion as to how to respond to the review and/or the denial of benefits, with a few parents seeking help from the schools and attorneys. A few parents had difficulty separating the notification of review from the letter of denial, with two failing to recall receiving the notification of review.

FINDING 27: Experiences with state and local Social Security Administration (SSA) offices generally proved problematic and confusing for parents.

Families ran into several problems in their dealings with the SSA and the appeal process. Hearings were rescheduled, files were lost, SSA examinations of the child were too brief, and correspondence was in English for Spanish speaking families. In Florida, during the appeal process, two families discovered that the SSA had incorrect diagnoses on file for their children. A few families described fearing the SSA, feeling threatened with having to pay back the benefits should they lose the appeal.

In New York, attending the hearings and other appointments with the SSA was somewhat problematic due to the distance families had to travel and difficulties finding transportation. Only two families reported having positive interactions with the SSA.

The amount of paperwork required for the appeal was overwhelming and time consuming and parents had little help from the SSA in completing the process.

“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 eight 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. You don’t know the details.”

Parents perceived contacts at the SSA as “talking down” to them. Many parents reported feeling that individuals at the SSA office, whether in person or over the telephone, treated them with little respect. A few parents expressed feeling “low” when they sought help, and even “lower” after making contact with the SSA office.

“No, I don’t know what’s going on! Because every time I try to make an appeal, it just seems like it makes it worse! But I haven’t done nothing. And then when you call them to find out what’s going on and they pretty much say, ‘this is the way it is, you owe this and you owe that,’ and then they hang up on you.”

FINDING 28: While there was a general feeling of distrust among families for the SSA’s ability to make an accurate determination of eligibility, there was also a pervasive belief that SSA was not very knowledgeable about the connection between the SSI cash benefits and Medicaid.

“I called them up and they sent me the forms. I filled them out and they told me I had to take him to a doctor...one of their doctors, although he was already seeing one, they wanted him to see one of their own.”

In response to the review process, some parents expressed concern about how the SSA conducted their child’s psychiatric evaluation. Many families felt that the review for their child was done unfairly or inaccurately. A few parents reported that their child was evaluated by someone that had never seen their child before and then only spent a few minutes to make the determination of eligibility.

“I feel it was a couple of weeks or maybe a month after it first came out on the news that I got a letter stating that B. was being re-evaluated, that he no longer qualified to be on SSI because under the new law, ADHD no longer qualified a child for SSI, and they said his CP was not severe enough to be on SSI. For five months they put me through pure misery. They sent him to that IQ testing. They had a psychiatrist that has never seen [the child], or evaluate his paperwork, and they were going to cut off his SSI because they said I had him on medication. Since he’s on medication, and since he’s in a controlled environment such as SLD at school, he no longer qualified for SSI. That is the stupidest thing I’ve ever heard.”

Families did not feel they received accurate information about how the changes in SSI were going to effect their Medicaid eligibility and did not receive assistance in how to apply for Medicaid or coverage through other eligibility doors.

FINDING 29: The SSI review process required a lot of “waiting and wondering” causing increased stress.

Parents were frustrated over having to wait for the outcome of the review or appeal, as it would have a major impact on their action plan, including their living and employment situation. Waiting resulted in parents feeling stressed and even depressed, with some being worried and tired of fighting.

“Well, I think probably my depression has escalated and I am on medicine now for it.”

Two mothers experienced a great sense of relief when they decided not to pursue benefits further after losing their appeals. They no longer had to fear future reviews or go through the tedious and stressful process of gathering paperwork to support their children’s disability.

“And the lady [hearings office] goes, ‘I didn’t realize you’d been waiting this long.’ I asked her, ‘how long until I know something, cause we’ve been waiting like a year and a half.’ I mean, a long time. So, anyway, she said that since I’d waited so long she’d try to have an answer to me probably, you know within 6 weeks or so. Which in the next week I got a notice.”

Finding 30: The SSI review/appeal process was lengthy, with outcomes that extended beyond the review period.

At the end of the study, two families were still awaiting the outcome of their latest appeal.⁸ Thirteen families in the study had retained their benefits, while two were repaying benefits to the SSA. Three families in New York had been instructed to repay benefits received during the appeal and it was unknown if they were aware of or applying for waivers.

⁸ Families could appeal up to three times.

“When they said they were going to review him, the first letter, it just said, ‘we’re going to review him, don’t do anything yet.’ So I waited, and then they said they’d send something else, so they did. And I guess a month later or so, they sent something else, and that’s when they said, ‘your son doesn’t deserve disability benefits anymore.’ I’m not exactly sure how they worded it. End of story.”

Near the end of the study, a few families were still considering additional appeals, while others had abandoned appeals in favor of making a new application for benefits. In some cases, this was motivated by changes in their child’s diagnoses, or advice from their support system.

“I thought that it was good for the next three years and thought they were not going to bother me again for that time. I told the lady that it has not been even a year since the last revision and they have never called my friend Mary and she is still waiting for an answer to hers. She has two kids.”

One mother waited a full year to have a hearing on her first appeal after experiencing delays caused by the SSA and her attorney. She believed her appeal was successful primarily due to her persistence and determination. She persisted primarily because of the Medicaid benefits, which her son had automatically qualified for as an SSI recipient prior to PRWOA, and which she believed he would lose. The SSI benefits not only provided much needed help and Medicaid coverage for her son, but gave her greater earning power than if her only option for Medicaid had been through the AFDC (TANF). However, she remained frustrated with the income limitations that accompanied the SSI benefits, as they did not allow her to earn enough money to improve the financial situation of the family without the loss of Medicaid. She reported that, in the absence of Medicaid, the costs for her son’s mental health care and medication would have exceeded the income from full-time employment.