

## Chapter Two Profiles of Children Receiving SSI

Emily Rodgers, Kevin Sweet, Joshua Harper, Patricia Santos, Sarai Ortiz, Michael Murphy, Scott Wilson, and Eugene Wheeler have two things in common. They all receive SSI benefits, and their parents are among the 45 family members who came forward to talk with the Commission about their experiences with the SSI program.<sup>1</sup> The following profiles introduce these children. While broadly representative of the families who testified before the Commission, these profiles are not intended to represent the SSI population as a whole. Rather, they offer a glimpse of the lives of families who face special challenges, demands, and rewards each day in raising a child with a disability at home. They demonstrate the parents' determination and the role that SSI benefits play in their efforts.

\*\*\* Emily Rodgers is six years old. She appeared before the Commission in Baltimore with her mother, Carlita Rodgers, in her wheelchair. She has cerebral palsy, severe mental retardation, and is blind. She must be fed through a feeding tube. Five weeks after her birth, she was hospitalized for pneumonia and has had seizures every day since her release. Rather than improving as she matures, her health has steadily deteriorated over the past two years. Ms. Rodgers stated that Emily's father was unable to cope with the challenges of Emily's condition and care, so he left the family. Emily and her mother now live near her maternal grandparents.

At one point, Emily's grandmother cared for her while her mother worked outside the home. Ms. Rodgers' health insurance did not cover equipment and many medical services that Emily needed, such as a wheelchair, a suctioning machine, and a nebulizer. Ms. Rodgers was able to buy the wheelchair with the help of contributions from some of her high school classmates. Her costs were "\$922 a month ... for [Emily's care, including] formula, her feeding bags, her diapers and her underpads ..." She had additional expenses for medications, pediatric visits, appointments with specialists, and hospitalizations.

Ms. Rodgers first heard about the SSI program through a seminar at Emily's school. She was elated when she learned that Medicaid might provide the services and supplies Emily needed that were not covered by her own HMO.

When Ms. Rodgers first applied for benefits, she was denied because her salary was too high. She was advised that she had three choices: quit her job, have more children to decrease her income in relation to the size of her family, or surrender custody of Emily to grandparents or strangers. Ms. Rodgers would not give up custody of her daughter. "Emily's my daughter and I'm not giving up my parental or custodial rights ..." She

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<sup>1</sup> This report uses both real and fictitious names of children whose families testified before the Commission. The families have given permission for these profiles to appear in this report.

eventually quit her job so that Emily could qualify for SSI and thus receive Medicaid. But she would like to be employed.

I look in the employment section every week and there are so many positions that I qualify for and I want to work so bad but I have to look at, if I worked, she loses everything ... I'm Emily's mom, she is my responsibility. My job now is to take care of Emily and see that she gets what she needs.

Ms. Rodgers supports Emily and herself from the \$336 check she receives from SSI and a \$212 child support check. For her own future and that of other parents of children receiving SSI, she would like to see the program restructured to provide services for children without penalizing parents who can and want to work.

\*\*\* Kevin Sweet is six years old and has cerebral palsy. He and his mother appeared before the Commission in Washington, D.C. He is a lively child who occasionally twists and turns in his stroller. His mother calms him by tickling his cheek.

His mother, Dianne Nichols, is a young, single parent of two children. Kevin was awarded SSI benefits after testing showed his mental age to be nine months. He spends most of his time in his wheelchair or stroller.

Ms. Nichols is employed at a motel and earns five dollars per hour. She explained that she uses her son's SSI benefit of \$201 per month to purchase diapers, child care, special foods, vitamin supplements, and medication. In addition, she says SSI provides "speech and physical therapy and medical equipment to assist him at home to working towards becoming the most he can be and as productive as he can be in his lifetime, which is what we all want for our children."

Without her son's SSI benefit, Ms. Nichols fears that she would be unable to bear the cost of caring for him at home.

Financially, if Kevin did not have his SSI, I could not keep him. That would be a very bad thing. It would be a loss of a family member. I'm sure you all have kids. It would be as if you had lost one of yours. No matter how [far from] normal, it's still a loss. You love them just the same, and you can't deny them the right like you wouldn't deny your other children the right to be the best that they could become, and that's through dedication, through monies from SSI to be able to give to these children.

\*\*\* Joshua Harper is a 16 month old with Down syndrome. He also has two holes in his heart. At the Commission's Philadelphia hearing he sat attentively in his mother's lap, although at times he became restless. Sharon Harper is a single mother. The SSI benefit she receives for her son allows her to be employed part-time and thus to spend time at home caring for Joshua. She values the time she spends with him, because she believes that their personal interaction is critical to his development. She also uses his SSI benefit to buy toys that grab and sustain his attention. She said:

By having the SSI, I am able to get equipment for him, I am able to keep a roof over our heads and food in our mouths basically ... I take him on bus rides. I take him to the Please Touch Museum. I -- you know, he likes Barney, so I have to buy video tapes of Barney because it makes him get up and crawl. It makes him want to do things.

In response to questions, Ms. Harper expressed apprehension about a state block grant that would provide services in lieu of SSI cash benefits.

I hear about block grants and money going back to the states and things like that. But what I find out is when I request something from the state, it takes me six to eight or longer weeks before I get anything, and that's holding up his development. So I go buy it. It's easier. And then I don't get it from the state. I don't get reimbursed. I go buy it. That's what the SSI money is for. You know, he needed a special chair. It cost \$200. I bought it.

Ms. Harper concluded, "You know, we live in a nice neighborhood, and I am the working poor... I know if SSI is done, we're homeless. We're homeless."

\*\*\* Patricia Santos, a sixth grader, is enrolled in special education classes. She has a depressive disorder which began when her mother became ill with cancer and worsened with her mother's death. Patricia now lives with her grandmother, Sarah Pitt. Ms. Pitt quit her job to care for her daughter during her illness and to raise her granddaughter. She says that she is able to care for Patricia because of the SSI benefit she receives.

Ms. Pitt uses Patricia's SSI benefit to cover the costs of basic necessities, medicine, and psychological services. Patricia's grades have slipped since her mother's death, so Ms. Pitt bought Patricia a computer to help with her school work. SSI also helps to cover the cost of the medication that Patricia's doctor has prescribed for her depression, psychological counseling three times each week, and transportation to and from these appointments.

Patricia's grief over the loss of her mother continues to affect her performance at school. School officials have requested that Ms. Pitt or another relative be present at school so that Patricia does not disrupt the class. Ms. Pitt stated, "... they ask that I be there for her, and I want to be there for her because she's grieving over her mother right now."

\*\*\* Sarai Ortiz is a small, thin 16-year-old who was born with severe asthma and cerebral palsy. She lives in Philadelphia and has received SSI payments throughout her life. Doctors predicted that Sarai would never walk. However, after having undergone surgery eight times to correct problems with her legs, Sarai walks. Her gait is uneven, but she is fully mobile.

Sarai's mother, Evelyn Sostra, testified before the Commission about how SSI has helped her daughter.

Our family has fought to make sure that Sarai has the same opportunities that other children have... SSI has made this fight a success ... Throughout her life, she has needed special braces for her shoes and special braces for her legs and specially designed shoes. The shoes and braces are very expensive and she's needed new shoes constantly and braces throughout the years as she grows ... SSI helped us pay for Sarai's braces and shoes ... When she was recovering from her surgeries, we had to rent wheelchairs and special walkers for her. Those rentals were very expensive. SSI helped us pay for them. When Sarai was growing up, she had difficulty swallowing and had to have special foods so she wouldn't choke. SSI helped pay for the special food she needs.

Sarai is an honors student in the eleventh grade. She competes on the school debate team and volunteers at local day-care centers. She plans to attend college and to become an attorney.

According to Ms. Sostra, SSI has enabled her daughter to grow and mature. She said, "In a few years, Sarai will be independent. If she had not had help from SSI, that wouldn't be possible."

\*\*\* Robin Murphy is the parent of three children: Lucas (14), Page (11), and Michael (8). Mrs. Murphy receives SSI for Michael, who was diagnosed with severe cerebral palsy at age 13 months. Michael's SSI benefit helps to cover expenses related to orthopedic impairments, including numerous doctor visits.

The Murphy family lives in a rural area and incurs substantial expense associated with transportation so that Michael can get treatment. All of Michael's limbs are affected, and he must use a wheelchair for mobility. The family has spent \$300 to rework door frames so that Michael can use his wheelchair at home. Mrs. Murphy would like to modify the family van, but at a cost of about \$500 for a ramp or \$5,000 for an electric lift, this remains unaffordable. Michael requires constant care and depends on others for many types of assistance. Mrs. Murphy explained:

My son requires special equipment for eating, seating, bathing, mobility, just to give you a few ideas of what types of things he uses. Toileting for a child who has a physical disability especially is a lot harder and this can go on for years. It's not like with a normal toddler. You work on it for three or four months and he's potty trained. My son we've been working on for three years and he's still not, so he's still in diapers and he's eight years old.

Mrs. Murphy defended her son's SSI benefit of \$76 per month, arguing that at a minimum, a foster care provider would receive \$1,000 per month. Foster care providers also would have access to unlimited nursing services and respite care, while families who receive SSI are limited to 12 hours per month. According to Mrs. Murphy, minimum care at the nearest residential facility costs \$65,000 per year.

Mrs. Murphy worries that the family might lose Michael's SSI benefit temporarily if her husband has an extra pay period in a month. Mr. Murphy must also refuse salary increases and promotions for fear of losing Michael's SSI eligibility and Medicaid. When asked what would happen if the family lost Michael's SSI benefit, she stated, "Well, we've been there before. We lost our home. We almost went to bankruptcy ... Going through this again, I don't know if I could handle this emotionally. My son would end up going into an institution."

Mrs. Murphy is convinced of the worth of the personal care she gives Michael. Without it, she feels, "He would revert so severely, I don't think he would ever come out again if that would happen."

\*\*\* Scott Wilson is a 15 year old who is depressed and emotionally disturbed. He lives with his parents and two younger siblings. Scott began to engage in disruptive behavior in the second grade. School officials recommended psychological testing and increased social activities. His mother saw to it that he joined the Boy Scouts and a baseball team, but she explained that despite her efforts, "... he was very withdrawn from the other children and he just couldn't socialize very well ..." Scott's third grade teacher reported that he was a good student but required one-on-one instruction.

Scott was asked to leave the school he was attending in the fourth grade. He entered another school but his disruptive behavior continued and, in the seventh grade, he was diagnosed as emotionally disturbed and depressed. After this diagnosis, Scott's mother applied for SSI.

Scott is currently in the ninth grade. Mrs. Wilson attends parenting workshops to learn behavioral management techniques. She also meets regularly with a school social worker and a psychiatrist to discuss ways to keep Scott on task and encourage him to be independent. Mrs. Wilson quit her job in order to respond to frequent calls from school to help control Scott's behavior.

Despite weekly therapy sessions, Scott has been institutionalized twice. Upon his return home the second time, he threatened his parents. They were so fearful that they hid all knives in the home. Scott's mother explained:

My son doesn't understand why he is the way he is ... he wants to be regular or normal, he just doesn't understand why, he doesn't know -- he wants to know why he was born to have to live this way.

Mrs. Wilson uses Scott's SSI benefits to pay for his eyeglasses, clothing, school supplies, transportation, and social activities. His parents remain hopeful that therapy and medication will make it possible for him to cope with his illness and become increasingly independent.

\*\*\* Eugene Wheeler is five. He has chronic asthma, a speech impairment, and developmental delays. His mother, Charol Jamison, is a single parent who has found it difficult to hold a steady job because of her son's disabilities. Eugene's asthma attacks routinely require his day-care center teachers to call his mother, forcing her to leave work to care for her son. Ms. Jamison was fortunate in that her employer was understanding. As she explained:

I was a good worker, so my managers were very patient, even though I had gone way beyond the company's policies for calling up and leaving work. They were trying to work with me, but I could tell they were getting frustrated and eventually they would have had to terminate me. Finally, I came to the conclusion that I could not be in two places at once, and it came to the point where I had to decide whether I was going to stay within this position or whether I was going to take some time out to try to stabilize my son's condition.

Eventually, Ms. Jamison took a leave of absence. During this time, she came to understand what triggers Eugene's asthma attacks and how to prevent them from progressing. Through constant attention and close interaction with his doctor, Ms. Jamison was finally able to control his asthma. Eugene has required hospitalization just once in the past two years.

Ms. Jamison has returned to employment part-time. Eugene's SSI benefit allows her to spend time at home giving Eugene the special care and attention he needs while retaining her job. Ms. Jamison clearly sees the benefit to herself as well as to her son. She said, "I am a person -- I prefer working. I'm happiest when I'm working."

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These profiles illustrate the diverse needs of children who receive SSI. In some of them, SSI is necessary to provide food, clothing, and shelter. In others, it helps to cover the cost of needs resulting from a child's disability, such as medication and specialized transportation. The profiles also illustrate the potential overlap of a child's disability-related needs and his or her needs as a child from a low-income family. For example, all children need food and clothing, but some children with disabilities require extra quantities or special forms of such items. Finally, the profiles exemplify the potential seriousness of behavioral disorders and their impact on these children and their families.

Despite the diversity in the children's impairments and needs, the profiles are entirely consistent in one way: all demonstrate the deep commitment of families who are devoted to helping their children learn, develop, and become all that they can be.