



The Other Welfare

See other videos

THE OTHER WELFARE

Money and hard choices

More indigent families are turning to a children's disability program to get needed cash

By Scott LaPierre/Globe Staff
Photos by Joanne Rathe/Globe Staff



The Supplemental Security Income (SSI) program for children was created mainly for those with severe physical disabilities. But the \$10 billion in federal benefit checks now goes primarily to indigent children with behavioral, learning and mental conditions. Qualifying is not always easy -- many applicants believe it is essential that a child needs to be on psychotropic drugs to qualify. But once enrolled, there is little incentive to get off. And officials rarely check to see if the children are getting better.

DAY 1



STORY

Cash and hard choices in disability program for children

A Boston Globe investigation finds that a \$10 billion, federal disability program for indigent children has gone seriously astray. It is now a fast-growing alternative welfare system with troubling incentives - such as financial reasons to take psychotropic drugs. The top category for approvals is ADHD. (By Patricia Wen, Boston Globe)

- PHOTOS [Hard choices](#)
- VIDEO [Behind the series](#)



DISCUSSION FORUM

Share your thoughts

Leave a comment on our moderated discussion board.



CHAT

Chat

Globe Staff Writer Patricia Wen answered your questions.

DAY 2



STORY

Benefit increasingly goes to the very young

Preschoolers are the fastest-growing age group qualifying for a federal disability program, largely because of a 12-fold spike in cases of speech delay. The government is aggressively trying to help these young children, but spends little time to see if they're getting any better. (By Patricia Wen, Boston Globe)

- PHOTOS [Benefits for the young](#)
- CHAT@NOON [Patricia Wen takes your questions](#)

MAILBAG

Experts respond

A panel of policy experts answered your questions: MIT economics professor David Autor, Massachusetts General Hospital pediatrician Dr. James Perrin, Williams College economist Lucie Schmidt and Massachusetts Society for the Prevention of Cruelty to Children president Mary Lou Sudders. Read their responses.

DAY 3

STORY

For teenagers, a difficult balancing act

Many teenagers in this federal disability program dream of fulfilling careers and adult lives free of government dependency. But for now, they decline



INTERACTIVE MAP

Children's federal disability payments

Examine Supplemental Security Income benefits for children by state.



... part-time jobs, largely because they fear working will jeopardize their disability checks. Their families are poor and need the money. (By Patricia Wen, Boston Globe)

- [PHOTOS](#) Difficult balancing act
- [MAILBAG](#) Experts answer your questions

FOLLOW-UP



LATEST NEWS

- [10/28/11](#) [B](#) Children's SSI program examined
- [Testimony from the 10/27/2011 Congressional Hearing](#)
- [7/27/11](#) Series wins national journalism award
- [7/11/2011](#) Disability program, concerns on rise
- [5/24/11](#) SSI program is flawed, chief says
- [1/18/11](#) Some in Congress look into incentives in disability benefit
- [12/18/10](#) Brown calls for hearings on disability program
- [12/16/10](#) Congressman asks hearings on SSI benefits for youth
- [12/16/10](#) Murky Path to SSI fixes
- [12/16/10](#) Revamp Globe Editorial: SSI to help caregivers while discouraging abuses

OUR TOWN

Thorton Wilder's masterpiece at the Huntington

[Home](#) | [Today's Globe](#) | [News](#) | [Business](#) | [Sports](#) | [Lifestyle](#) | [A&E](#) | [Things to Do](#) | [Travel](#) | [Cars](#) | [Jobs](#) | [Real Estate](#) | [Local Search](#)

[CONTACT BOSTON.COM](#) | [Help](#) | [Advertise](#) | [Work here](#) | [Updated Privacy Policy](#) | [Your Ad Choices](#) | [Newsletters](#) | [Mobile](#) | [RSS feeds](#) | [Sitemap](#)

[CONTACT THE BOSTON GLOBE](#) | [Subscribe](#) | [Manage your subscription](#) | [Advertise](#) | [The Boston Globe Extras](#) | [The Boston Globe Gallery](#) | © 2013 NY Times Co.

A legacy of unintended side effects

By Patricia Wen

Globe Staff / December 12, 2010

First in a three-part series.

Geneva Fielding, a single mother since age 16, has struggled to raise her three energetic boys in the housing projects of Roxbury. Nothing has come easily, least of all money.

Even so, she resisted some years back when neighbors told her about a federal program called SSI that could pay her thousands of dollars a year. The benefit was a lot like welfare, better in many ways, but it came with a catch: To qualify, a child had to be disabled. And if the disability was mental or behavioral — something like ADHD — the child pretty much had to be taking psychotropic drugs.

Fielding never liked the sound of that. She had long believed too many children take such medications, and she avoided them, even as clinicians were putting names to her boys' troubles: oppositional defiant disorder, depression, ADHD. But then, as bills mounted, friends nudged her about SSI: "Go try."

Eventually she did, putting in applications for her two older sons. Neither was on medications; both were rejected. Then last year, school officials persuaded her to let her 10-year-old try a drug for his impulsiveness. Within weeks, his SSI application was approved.

"To get the check," Fielding, 34, has concluded with regret, "you've got to medicate the child."

There is nothing illegal about what Fielding did — and a lot that is perhaps understandable for a mother in her plight. But her worries and her experience capture, in one case, how this little-scrutinized \$10 billion federal disability program has gone seriously astray, becoming an alternative welfare system with troubling built-in incentives that risk harm to children.

A Globe investigation has found that this Supplemental Security Income program — created by Congress primarily to aid indigent children with severe physical disabilities such as cerebral palsy, Down syndrome, and blindness — now largely serves children with relatively common mental, learning, and behavioral disorders such as ADHD. It has also created, for many needy parents, a financial motive to seek prescriptions for powerful drugs for their children.

And once a family gets on SSI, it can be very hard to let go. The attraction of up to \$700 a month in payments, and the near-automatic Medicaid coverage that comes with SSI approval, leads some families to count on a child's remaining classified as disabled, even as his or her condition may be improving. It also leads many teenage beneficiaries to avoid steps — like taking a job — that might jeopardize the disability check.

The latest federal statistics, obtained by the Globe through a public records request, show a stunning rise over the past two decades in the number of children who qualify for SSI because of a variety of mental disabilities.

Of the 1.2 million low-income children nationwide who received SSI checks last year, 53 percent, or 640,000, qualified because of mental, learning, or behavioral issues, up from 8 percent in 1990. By significant margins, the top two disorders are Attention Deficit Hyperactivity Disorder, or ADHD, and delayed speech in young children, followed by autism spectrum disorders, bipolar illness, depression, and learning problems, according to the Social Security Administration, which runs this program and the \$55 billion SSI system for adults.

In New England, the numbers are even higher — 63 percent of children qualify for SSI based on such mental disabilities. That is the highest percentage for any region in the country. And here and across the nation, the SSI trend line is up, with children under 5 the fastest-growing group. Once diagnosed, these children often bring in close to half their family's income.

“This has become the new welfare,” said MIT economics professor David Autor. “This is a very valuable resource to families, but you’re providing incentives for them to produce a diagnosis for their children to be part of this program, and there’s also incentives to medicate them. This is a substantial public policy problem.”

This transformation of the children’s SSI program is viewed as a victory by many disability and mental health advocates, who have long pressed for serious cases of depression and learning disorders to be recognized alongside cerebral palsy and Down syndrome as major disabilities. The program’s expansion has also undoubtedly helped many new families cope with the exhausting needs of deeply troubled children.

“A few years ago, we never saw a bipolar diagnosis in a child; now we do,” said David Rust, a top Social Security official who defended the agency’s handling of the SSI children’s program in an interview with the Globe. “The world is changing in terms of who we serve and the kinds of conditions we see.”

But, the Globe review found, the changing nature of the SSI program has had some disturbing side effects. Many cash-strapped parents have come to believe that if only they can muster the necessary array of medical records, their children have a good shot at this benefit, even if it means carrying the stigma of the word “disabled.” And while some parents see their children’s behavior improve from psychotropic drugs — as has been the case so far with Fielding’s youngest boy — they bristle at the outsize role that these medications seem to them to play in securing SSI approval.

For many, the motivation to apply comes down to economics: SSI payments can be a lifeline in a bad economy, and they beat welfare checks in almost every way. For a Massachusetts parent with two children, welfare pays a maximum of about \$600 a month. If one of those two children is approved for the SSI program, the total government benefit can be twice as much.

“Everybody’s poor, everyone’s got issues,” Fielding said, as she sat in her family’s apartment near Madison Park. “People are going to try to get a check.”

Learning the system

At the beginning of every month, postal carriers drop more than 21,000 SSI checks on behalf of children into mailboxes across Massachusetts, mostly in distressed areas of Springfield, Boston, Holyoke, Lawrence, and New Bedford. Only youngsters living around the poverty level are financially eligible, and many of their parents, out of work or maxed-out on welfare benefits, have grown resigned to homeless shelters and food pantries.

The children on SSI represent a cross section of the poor. Federal data show that roughly half identified as white, half as black; some 16 percent self-identified as Hispanic. Two of every three recipients are boys, in part because ADHD diagnoses skew heavily male. And ADHD is the top diagnosis, constituting 31 percent of all children on SSI for behavioral, learning, and mental disorders.

As the Globe investigated the surge in SSI cases — mostly by visiting housing projects, Social Security offices, and downtown districts — many parents were reluctant to talk, fearful of losing this coveted benefit. Still, some two dozen families agreed to be interviewed, in part to vent their frustration at what they perceive to be the government’s arbitrary approval process in mental disability cases. Some wanted only their first names to be used as they described their persistent efforts to figure out what Social Security wanted, and their growing conviction that medication for the child was a critical step.

Waiting on a bench in a rundown commercial strip of Lawrence, Yessenia was among the frustrated.

The 28-year-old woman said late last summer that she will be trying, for the third time, to obtain SSI payments for her 7-year-old son based on his ADHD symptoms: impulsivity and inattention.

Yessenia said she is convinced her son’s first two applications were rejected because she had nothing to list in the section labeled “medications.” But in recent months, she has convinced the boy’s doctor to write a prescription. Her son is now taking a stimulant often used for ADHD.

“If you child doesn’t have medications, the SSI office thinks he doesn’t have any big problem,” she said.

Yessenia and her extended family have long experience with the SSI program. As a child, she said, she qualified for SSI based primarily because of learning disabilities, and after her 18th birthday, she requalified as an adult on the same basis. Her older sister, diagnosed with bipolar disorder, has been receiving SSI benefits since childhood.

Yessenia said she has other reasons to be optimistic that her son’s new application will be approved.

“Since he was denied all the time, the therapist said she’d give him another diagnosis, and that’s when she said he’s got depression,” said the mother, who has yet to submit the new application. “She’s also recommending another drug.”

Yessenia, and the others interviewed, insisted that they do only what is best for their children’s health and would never medicate purely to boost their SSI application. But some of the parents said they know of others who exaggerate their children’s symptoms so that clinicians prescribe medications or add additional psychiatric diagnoses.

“A lot of people do it,” said Makeysha, a Jamaica Plain mother whose child is on SSI for ADHD. “A lot of people don’t have income coming in.”

A special education teacher at Holyoke High School with two decades of experience said it is clear to her that indigent parents learn, through word of mouth, the strategic “ins and outs” of the SSI system. The teacher, who asked not to be named because she is not authorized to speak about student records, said she has seen hundreds of teenagers on SSI for mental disabilities.

“I don’t know anyone who isn’t on drugs,” she said.

She also said she is frequently asked by parents to complete SSI paperwork about a child’s academic level, in hopes that it will confirm a diagnosis for some kind of mental disorder.

A horrifying case

The incentives built into the SSI program and their potential hazards came into starkest relief in the case of a South Shore couple, Carolyn and Michael Riley.

Their story was horrifying and far from typical, but also telling about how a child’s mental health diagnosis can be abused in the name of money.

Each of their three children was, according to medical records, diagnosed with ADHD and bipolar disorder, and prescribed three powerful drugs. The parents made sure to highlight the youngsters’ prescription data in their SSI applications: “If not for medication, my son would not be able to sleep more than 3 hours in a 24-hour period,” Michael Riley wrote. The parents obtained SSI benefits for the oldest two children, and for themselves through the SSI program for adults. They were applying for benefits for 4-year-old Rebecca, when the girl turned gravely ill sometime after midnight on Dec. 13, 2006.

Rebecca had been sick with an respiratory infection, but the Rileys did not take her to a doctor. Instead, they fed her excessive amounts of clonidine, a sedating medication often prescribed for ADHD, to get her to sleep. She ultimately died of a drug overdose, and jurors this year convicted her parents of killing Rebecca with their reckless care. Records made public during the murder trials showed the parents’ casual approach to medication over years, and how their calculated pursuit of SSI checks and psychiatric pills caused them to exaggerate their children’s behaviors to clinicians, including a Tufts Medical Center psychiatrist.

Until the day Rebecca died, the family depended largely on SSI checks totaling roughly \$30,000 a year.

As extreme as their case proved to be, the way this family sustained itself financially is far from rare. As more

families are cut off from the nation's welfare benefits, millions of indigent parents have turned to SSI.

Said Williams College economist Lucie Schmidt: "It's become the de facto backup safety net."

Top officials in the Social Security Administration, in an interview this fall at the agency's headquarters just outside Baltimore, insisted they do their best to implement the Congressional mandates for the SSI children's program, which require sensitivity to a wide range of physical and mental disabilities, while approving only those children with severe impairments.

Art Spencer, associate commissioner in the agency's office of disability programs, said he was disturbed to hear that the Globe's review found that many indigent families are convinced that psychotropic drugs are critical in obtaining SSI benefits.

"Medication helps confirm a diagnosis, but most of the decision is going to be based on the child's function," said Spencer, whose agency's primary job is overseeing the nation's \$800 billion program for retirees' and other workers' benefits.

Rust, deputy commissioner in the office of retirement and disability policy, said each child's case is carefully reviewed by a disability examiner, as well as an in-house pediatrician.

He said that the agency does not currently track how many children on SSI are prescribed psychotropic medications, but that a new computerized record-keeping system may give them the ability to do so. Rust emphasized that, ultimately, awarding benefits rests largely on what the child's doctors and clinicians say about the child's impairment, and that the agency needs to trust that information. He said, on occasion, disability officials have spotted clusters of SSI families with the same doctors, and with strikingly similar diagnosis and treatments, and referred those for possible fraud prosecution. But mostly, he said, "We work off the medical evidence we get."

Rust, a former high school teacher, acknowledged, however, the risk that long-term SSI enrollment may exact a psychic toll.

"One of my concerns about the program is that by designating a child as being disabled, it creates a certain mindset with the child, with the family, with the schools. . . . You're disabled. You are unable to do certain things," he said. "I really do worry, in the program's attempt to help children, and that's what we're trying to do, we can create a certain psychology of disability that is hard to break."

A subjective scale

It is easy to see why indigent families are confused by eligibility rules — and looking for a shortcut to SSI approval.

On paper, the eligibility requirements are daunting. According to the most recent Social Security rules, passed in 1996, a child can be approved for mental disability benefits only if he or she has a "medically determinable impairment that results in marked and severe functional limitations." The impairment should be one that persists for at least a year or may result in death.

In some instances, a specific diagnosis for a severe condition — schizophrenia, for example — is a virtual and uncontroversial guarantee of benefits. But most diagnoses are not of that severity and SSI approval hinges on the highly subjective determination of whether a child's condition, or cluster of conditions, amounts to a "severe" impairment.

Officials wade through piles of medical, clinical, pharmacy, and school records, some haphazardly or partially completed, to determine how a child functions in six designated "domains," such as how well he or she communicates, or gets along with peers, or can take care of his or her own basic needs. One "marked" impairment is not enough for SSI approval, but a "severe" impairment in one domain, or, alternatively, "marked" impairments in two domains, is.

Officials may also rely on standardized neuropsychological and other tests or hire an independent medical expert to evaluate the child. Nevertheless, in many cases, diagnoses are based largely on a parent's account, and disability evaluators never meet the child face-to-face.

Jennifer Erkulwater, a coauthor of the Harvard University Press book "Medicating Children," about the rise of ADHD diagnoses nationwide, said it is easy to see how psychotropic drugs have turned into a potential marker of a mental disorder's severity.

"If the doctor says it's serious, he's giving a prescription," said Erkulwater, a political science professor at the University of Richmond.

She said it is unclear whether the SSI approval process is a factor behind federal data showing that indigent children are diagnosed and prescribed psychiatric drugs at a higher rate than more well-off children. A 2008 study found, for example, that 12 percent of children on Medicaid were diagnosed with ADHD, compared with 8 percent of children on private insurance. Other national studies using Medicaid data have found that poorer children with behavioral and mental diagnoses are also medicated with ADHD drugs and antipsychotic medications at higher rates.

Erkulwater said researchers have cited many explanations for this difference, including the possibility that doctors are more inclined to medicate poor children or that higher rates of mental disorders exist among the destitute. She said that "among the nexus of reasons" is that indigent families may be more open to psychotropic drugs if they believe a prescription will help a child's SSI application.

Patrisha Thompson, a Fall River mother of two, cited another reason why poor families may be quicker to medicate their children for behavioral problems: They don't have the time for bus or subway rides to talk-therapy sessions, and they know that counseling sessions are unlikely to impress a disability examiner.

Thompson, 28, said her job in the health care industry made her realize the importance of trying behavioral therapy. She took her sons to such sessions before agreeing reluctantly last year to let her sons start a prescription of an ADHD medication. She has since put in SSI applications for both boys, ages 7 and 10, whose diagnoses also include depression, anxiety, and learning disorders. But many indigent parents, she said, do not realize that there are alternatives to drugs, or don't have the time to pursue them.

"It's easier to medicate," said Thompson, recounting what she hears from other parents.

Thompson is still waiting to hear how SSI rules on her oldest boy's application. Her 7-year-old boy was denied, she said, adding that she was not given a reason.

She said the denial may indicate that drugs are not a decisive factor. But she said that, based on her knowledge of other cases, an application with no mention of drugs has "little to no chance" of success. Even if both sons' applications are denied, she said, she is grateful that her job gives her enough income to provide the basics. But she can understand why others, more impoverished, seek SSI approval.

"Money determines everything," she said. "It determines how much you eat, what you eat, and how you treat your kids."

Landmark ruling

The federal disability program for poor children was born four decades ago, shortly after Congress rejected President Nixon's groundbreaking 1969 proposal for a guaranteed minimum income for the poor.

Instead, as a compromise of sorts, federal lawmakers approved the Supplemental Security Income program for the elderly, as well as for blind and disabled adults. Some early drafts of the proposal made no mention of children. But at the 11th hour, and virtually as a footnote, lawmakers in 1972 designated disabled children eligible for SSI payments.

The idea was that the benefit would help replace wages lost by indigent parents as they took time out to care for children with severe physical and congenital disabilities, such as cerebral palsy, muscular dystrophy, and deafness, or those with life-threatening illnesses, such as cancer. The money was also seen as a way to help families with extra expenses, such as wheelchairs or taxi rides to hospitals.

It remained for many years a relatively small, highly restrictive program; as late as 1990, it served fewer than 300,000 children, and only 8 percent qualified based on behavioral or mental disorders.

Then, after a landmark legal ruling, the ground began to shift.

The case grew out of a campaign in the early 1980s under President Reagan to reduce SSI rolls. Social Security officials, responding to the new mandate, cut off Brian Zebley, a boy who had been receiving benefits since he was toddler, ruling that he was no longer disabled despite a variety of physical and intellectual disabilities. His family's lawyer challenged the fairness of the eligibility rules, arguing they were too adult-oriented and rigid, and in 1990, the US Supreme Court agreed. Social Security authorities then rushed to implement new, looser rules, and also widened eligibility for children's behavioral and learning disorders.

A subsequent spike in mental disability cases led to a national uproar. Media accounts described parents coaching their children to misbehave or flunk tests. Some of those who desired change wanted ADHD cut from the list of allowed SSI diagnoses, arguing that the condition was not typically severe, and that its inclusion was leaving the system vulnerable to an explosion of claims. But they were drowned out by advocates for the disabled. Meanwhile, some federal authorities raised concerns about the program's potential to harm children.

"Here the moral hazard is that the family may become dependent on SSI, and in order to continue to receive payments, decline to seek treatment aggressively or fail to encourage a child to do his or her best to overcome a disability," said Jim Slattery, a former congressman and chairman of the National Commission on Child Disability, during a 1995 hearing.

By the mid-1990s, federal lawmakers were cracking down.

Congress passed tougher standards for SSI mental disability disorders, saying a child now had to exhibit a "medically determinable" disability with "marked and severe" limitations. These changes were included as part of sweeping 1996 welfare reforms.

The children's SSI disability rolls instantly shrunk — but the decline would be short-lived. Families and clinicians began to adjust to the new rules, which emphasized extensive medical records for any claimed disability. From 1997 to 2007, the number of children who qualified under behavioral, mental, and learning disorders more than tripled from 180,000 to 562,000. By last year, more than 639,000 children were on SSI, 53 percent of all cases.

This abrupt climb in cases is a sign, some researchers say, that the SSI program has veered far from its original purpose.

Dr. James Perrin, a Massachusetts General Hospital pediatrician who has served on federal panels evaluating the SSI program, defended the program, saying it cares for many of the most vulnerable youngsters. One of SSI's main benefits, he said, is providing near-automatic Medicaid coverage for disabled children. But he said some aspects of the program may need to be reconsidered, including the no-strings-attached cash benefit.

"Families with children with disabilities have real needs for additional income - but perhaps that money should be linked to meeting the specific needs of the child's disability and, where possible, to supporting that child's transition to productive adult life."

'Driven by the dollar'

The pressure on medical professionals to help families make the case for SSI approval can be considerable.

One nurse practitioner in a large urban clinic who asked to be unnamed because she is not authorized to speak about her patients said she recently faced the wrath of a parent whose 4-year-old child's SSI benefits, granted at birth due to prematurity, were cut off because the child was much better now. The nurse said she had candidly filled out the SSI form about the child, saying the boy had caught up with his peers and had only "minimal deficits." The mother was livid, shouting at her, "Don't you think this child's disabled?"

"They get angry with us," the nurse practitioner said.

One diagnosis she believes is seriously overused is "the whole vague developmental delay" category for young children, often preschoolers who are behaving badly at home or in day care for undetermined reasons. She said clinicians often attribute such behavior to developmental delay, especially if they are sympathetic to that family's needs for SSI payments.

"It's all driven by the dollar," she said.

Many doctors, therapists, and social workers say they are well aware of the impact SSI benefits can have on indigent families. Indeed, some clinicians said they often feel pressure to upgrade a diagnosis or tailor the SSI paperwork to increase the odds of approval. Some say they go that extra mile because they believe that furthering the financial stability of needy families is essential in helping a troubled child.

"Some psychiatrists do feel these people are entitled to benefits," said Judy Rolph, a pediatric psychiatric nurse in Boston for more 30 years. "You know these people are poor."

Also pushing hard for SSI approvals is the growing number of for-profit firms that specialize in helping poor families tap into SSI benefits. These companies, which call themselves "eligibility service providers," are hired by hospitals, which stand to lose money when caring for uninsured patients. If these firms successfully obtain SSI benefits for an uninsured child, the youngster's medical bills are paid by Medicaid. The reimbursement rates are even higher if the child is deemed disabled.

Health insurance companies, which administer Medicaid plans, also sometimes hire these firms, for similar financial reasons.

State welfare department officials also often urge poor families to apply for SSI benefits on behalf of their children. There, too, money is the motivation. An indigent child cannot be on both welfare and SSI at the same time, so states save money if a child goes on SSI, which is entirely paid for by federal funds. The cost of traditional welfare is covered by state and federal money.

Such help with the SSI application can be critical for parents, many of whom are at a loss to complete the complex paperwork.

Giselle Cabrera, a family services coordinator at the Head Start preschool in Holyoke, who helps families with SSI applications, sees firsthand how parents struggle to complete certain SSI forms and wonder how candid to be about their children's symptoms. They are often desperate, she said, and often medication is what they believe will help their child's case.

"It's very frustrating for parents," she said.

'It's all about surviving'

Sitting in her apartment near Madison Park, Geneva Fielding is surrounded by stacks of well-organized SSI files for her three sons. She continues to be torn about medicating her youngest. Tucked among her thick files is a favorite article, titled, "What if Einstein had been on Ritalin?"

She acknowledges that her youngest boy is focusing more on his schoolwork, and that doctors say his dosages of Concerta are safe. But still, she says, she wants to stop these drugs as soon as possible. She says she does not worry if her benefits, in the future, are cut.

“God’s been good to me. If they cut me off, I’ll be all right,” says Fielding, who is active in parent and neighborhood groups.

As she folds laundry in her three-bedroom apartment, she says she believes her middle child, the 14-year-old, has the greatest mental disabilities. He has been diagnosed with dyslexia, and he struggles with reading. He also has asthma and emotional issues. She worries he will wind up illiterate, like her father. His SSI application has been rejected, but she is appealing.

Fielding says the SSI checks have helped get her through difficult economic times, but she has mixed feelings about the role they play among poor families. She says she decided to speak to the Globe to highlight the worrisome incentive to prescribe children drugs.

“Sometimes I don’t know why we get a check for this,” she said, referring to her youngest son’s case. “But if someone says you have ADHD and you’re depressed and you can get a check, they’re going to try to get a check. The poor people will take that every time. It’s all about surviving.”

Patricia Wen can be reached at wen@globe.com.

© Copyright 2010 Globe Newspaper Company.

A coveted benefit, a failure to follow up

By Patricia Wen

Globe Staff / December 13, 2010

Second of three parts

HOLYOKE — Her toddler was adorable and rambunctious, but his vocabulary was limited to “Mommy” and “that,” while other children his age knew dozens of words. When little Alfonso tried a full sentence it came out in a swirl of sounds, often followed by a major league tantrum when he realized he was not understood. And so his mother, Roxanne Roman, was not surprised when the 18-month-old was diagnosed by a specialist with speech delay.

It came as a shock, however, when she learned from relatives that Alfonso’s problem might qualify him for thousands of dollars in yearly disability payments through the federal Supplemental Security Income program. For Roman, pregnant with her second child at age 17 and living at her mother’s, the extra income was attractive. She wanted to rent her own place.

Within three months, the boy’s application was approved. Alfonso receives \$700 in monthly cash benefits, plus free government-paid medical coverage. Roman said her relatives told her she can pretty much count on the disability checks for Alfonso, now 5, to keep arriving in the mailbox for the rest of his childhood.

“They don’t ask many questions about the child once you’re approved,” Roman said.

Alfonso is part of the wave of very young children swelling the ranks of this \$10 billion disability program — once primarily for those with severe physical disabilities but now dominated by children with behavioral, learning, and mental disorders. Children under 5 are the fastest-growing age group qualifying for SSI benefits, representing four of every 10 new cases, according to data obtained from the Social Security Administration, which runs the program.

Driving much of that growth is the twelvefold spike since 1997 of children approved based on a primary diagnosis of delayed speech, a sometimes persistent but more often short-lived affliction that starts in toddlerhood.

It is a program with the idealistic goal of helping needy families with disabled children, part of the federal government’s broader drive to intervene early in such cases. But a Globe review has found that while SSI provides a coveted financial benefit for growing numbers of the very young children, it largely fails to monitor their progress or to guide out of the disability system those whose condition has improved.

Government data show that Social Security officials have, over the past decade, fallen far short when it comes to conducting the regular case reviews required by statute. A typical SSI disability case is supposed to get a full medical review every three years, but from 2000 to 2008 the agency examined, on average, only 10 percent of the children on SSI.

In both 2007 and 2008, the review rate dropped below 1 percent, and preliminary data suggest the record for the last two years is just as low. In fact, a Social Security study of children receiving SSI until age 18 found that some 40 percent never had even one disability reevaluation during their childhood years.

The importance of such reviews becomes obvious when Social Security does get around to conducting them. Agency staff typically find that one of every four children no longer meets the agency’s disability standards, though that ruling is often appealed by the parents.

The reviews are also considered a vital opportunity to check that a child’s treatment regimen is appropriate, and to monitor his or her progress, or the lack of it.

“The goal is to get kids help and see them improve,” said Julie Boatright Wilson, director of the Malcolm Wiener Center for Social Policy at Harvard’s Kennedy School and a specialist in poverty policy. “By not checking up, they’re sending the message of entitlement.”

Several researchers who study family poverty said the SSI program deserves praise for trying to help the youngest of children, but they worry that it tends to pull them into a longstanding relationship with a disability system. Many early childhood specialists were stunned to learn that speech delay had become such a popular gateway for children’s SSI benefits and suggested that that may be because it is the easiest-to-measure impairment among preschoolers.

Some go further and suggest that delayed speech is being used as a catchall diagnosis for preschoolers with both communication and behavioral problems, and that it is often employed by clinicians loath to attach a psychological interpretation to the symptoms of children so young.

“It’s a fear of labeling,” said Dawn Thomas, a project coordinator of an early childhood program at the University of Illinois and author of an extensive study on disability programs at Head Start centers. “But a speech and language diagnosis can hide the real issues.”

Wilson said she worries that Social Security officials, preoccupied with their financially shaky \$800 billion annual operation for retirees’ and workers’ benefits, are ill-suited to manage a disability program with such serious repercussions for children.

“It’s not the centerpiece of what they do,” she said.

Indeed, despite the program’s focus on disability, the payments are not reserved only for disability care. Many parents use the money much like an ordinary welfare benefit, spending the SSI payments on general household expenses such as rent, food, clothes, and diapers — and federal rules permit them to do so. The only benefit that directly targets the child’s disability is the Medicaid coverage that almost always comes with SSI approval and which pays for a range of disability services.

“You got to do more to get into the [SSI] program, but once you do, it’s an easier and better form of welfare,” said Shauna Lougee, a Holyoke mother whose toddler was approved for benefits this summer after he was diagnosed with speech delay and potential signs of autism. “You get more money, and they don’t check up on you.”

At a Social Security Administration waiting room in Lawrence one day this summer, the mother of a 9-year-old girl said her daughter was approved quickly for SSI payments as a toddler with speech delay and has never had a full review of her disability status.

“Nobody has ever checked,” said the mother, who asked to be identified only as Tina for fear of triggering an investigation of her case.

The mother, who came to the office to report a new address, said Social Security officials frequently contact families to see if they are earning extra wages on the side, which can affect the size of the SSI check. But she said she has never had a doctor, clinician, or speech therapist tell her about the need for a disability review of her daughter’s case.

When asked if she thinks her daughter is still severely disabled with her speech, Tina replied hesitantly, “No.” She said her daughter still has trouble pronouncing her R’s — which come out sounding more like W’s — and still receives speech therapy for what the mother called a moderate problem. But the girl can be easily understood by most people and performs at grade-level in her public school.

“I know she’s not severely disabled anymore,” the mother said. “It’s an interesting thing, really, that she does still qualify. She gets better and better.”

Based on SSI rules, a child's speech delay can result in new or continued benefits if testing documents a "severe" impairment. For a child under 3, for example, federal authorities often consider a severe case to be one in which the child speaks like someone half their age, or younger.

A less serious speech delay may also qualify, but only where the child suffers from other physical or mental problems that result, together, in a severe level of overall impairment.

Tina, whose family was on the brink of homelessness in August, said she will not voluntarily tell Social Security about her 9-year-old daughter's improvement, nor that she still gets checks for her younger son, who qualified as an infant with developmental delay and has now caught up with his peers. She is not legally required to notify SSI about any perceived progress, nor are doctors or clinicians required to report such changes.

The mother said she desperately needs the SSI payments, which add up to about \$1,400 monthly. If the checks stopped, she said, she would cope — but with great difficulty.

"I'm not a really educated person, so it's not easy to get a job," said the mother, who has a GED and has held a job at a gas station. "But I'd have to deal with it. I'd be stressed. I'd be asking, 'How do I get a job?' And maybe, 'Does anyone have a job from 8 to 2:30 p.m., so I can pick up my kids?'"

An enormous challenge

Social Security Administration officials say that they realize there are flaws in the SSI disability program for children, but that they believe they have, overall, managed its complexities well despite the deluge of new applications — nearly 550,000 last year, up 15 percent from the year before.

"For the system we run and the volume of the cases we handle, we do a very credible job," said David Rust, deputy commissioner in the agency's office of retirement and disability policy.

Officials said they recognize that the lack of disability reviews is a major problem, one they tie to a shortage of staff and funds. They said they must persuade Congress to award more funding for these reviews or find the money another way.

As for the increasingly commonplace diagnosis of speech delay, Rust said it would be too simplistic to think that most children in the category had just this one impairment. Many of the children also have ADHD and behavioral and learning disorders, though they may be listed as secondary diagnoses and not captured in computerized data, he said.

Rust, in an interview at the agency's sprawling headquarters just outside Baltimore, also said it is an enormous challenge to serve as arbiter of what constitutes childhood disability. When the SSI program began four decades ago, it largely served children with severe physical disabilities such as cerebral palsy, Down syndrome, and blindness, as well as those with profound intellectual deficits, including low IQ. Since the 1990s, the agency has faced strong political pressures from disability groups and mental health advocates to expand the list of eligible behavioral, learning, and mental impairments for children.

Rust said the fact that such mental disabilities now represent 53 percent of all children's SSI cases largely reflects the changing definition of disability within American society. And he conceded that there is, inevitably, some subjective judgment in the decision-making process.

"We would love it if there was a test for every condition," Rust said. "There are very few of those in our business."

Early intervention

The Western Massachusetts city of Holyoke, one of the poorest in the state, provides an extraordinary window into how the SSI disability program works for some of the youngest children, for better and for worse.

Here, 1 of every 5 children living in poverty receives SSI disability benefits. And of the 939 children who

qualified last year, 699, or 74 percent, were approved for behavioral, learning, or developmental delays, data show — the highest percentage among all ZIP codes in Massachusetts. One of three of those on SSI was approved after a diagnosis of speech delay, according to federal data obtained by the Globe through a public records request.

This former mill town has no shortage of need, particularly among young mothers. A commercial thoroughfare this year featured a banner proclaiming, “Holyoke supports the National Campaign to Prevent Teen Pregnancy.” Amid the boarded-up storefronts, signs promote prenatal services.

There are no billboards about the SSI program, but when a mother from a low-income household mentions a child diagnosed with speech delay or another disorder, it is often not long before someone — a neighbor, clinician, day-care teacher or social worker — tells them about the possibility of SSI benefits.

Oneida Rivera, who lives in one of Holyoke’s toughest housing projects, said her daughter was 2 when she was diagnosed with speech delay through a federally funded early-intervention program. During a subsequent meeting that included her daughter’s Head Start teacher and other specialists, she was told about the possibility of cash benefits.

“They told me, ‘You can apply for SSI,’ ” said Rivera, whose daughter, 4, was approved in August for more than \$700 a month.

The frequency with which preschoolers like Rivera’s daughter are identified with speech problems is related in no small part to the thousands of federally funded early childhood specialists nationwide, whose admirable mission is to catch troubles in children as early as possible and provide intensive services. Speech delay, compared with other disorders, is relatively easy to assess by judging word counts and how clearly a child articulates.

The \$7 billion Head Start program, for instance, is required by congressional mandate to set aside 10 percent of its slots for preschool children deemed disabled. If a Head Start center does not fulfill that quota, designed to show the program’s commitment to helping the full range of children, that center’s federal funding is threatened. Often there are simply not enough cases of children with severe physical disabilities, such as Down syndrome or deafness, to come close to meeting the 10 percent threshold.

The Head Start centers do not have to meet the 10 percent target on the first day of each school year. They have several months into each school year — enough time for specialists to screen students or get referrals from elsewhere — to attain sufficient numbers.

Most centers do reach this level, but barely. Of the 1,100 children served by the Head Start centers covering Holyoke, Springfield, and Chicopee, 113, or 10.3 percent, have been identified as having disabilities, officials said. Among those, 90 percent are listed with speech or developmental delays. Head Start centers across the country have a similarly high percentage of children with these diagnoses.

Thousands of Massachusetts children are also identified with speech delay each year through the federal government’s “Child Find” early-intervention program, created through the Individuals with Disabilities Education Act. This program hires staff members to actively look for children from infancy to age 3, regardless of income, who may need special services.

Nora Moreau, a disability specialist at the Head Start center in Holyoke, said some parents, at first, are alarmed when informed their child has a disability, even though staff members try to break the news gently. Once the parents adjust to the diagnosis, Moreau said, many soon hear about the SSI program and apply for benefits. She said parents generally apply on their own but often ask Head Start to submit paperwork to back up the disability claim.

“We do submit paperwork when they ask,” Moreau said. “Overall, it’s smooth. We haven’t had many calls from the SSI office asking for more information. I haven’t heard any complaints.”

A determination by Head Start that a child has a speech delay, however, is not a guarantee of monthly SSI benefits, because the federal preschool program's threshold tends to be slightly lower than Social Security's.

Some researchers worry that a diagnosis of speech delay may obscure the root cause of the child's problems and could lead to ill-advised treatments. A child's speech delay, for instance, may be due to a home environment in which few adults speak to the child, the result of emotional trauma within a volatile family, or an outgrowth of a neurological disorder.

Clinicians, they say, often resort to using "speech delay" because it is the least-stigmatizing diagnosis. Lori Chaves, head of clinical and support services at the Head Start center in Holyoke, added, however, that children with behavioral troubles often also display serious speech problems, an intertwining of issues she has witnessed increasingly over the past 15 years.

"With a lot of mental health diagnosis, we see a lot of communication disorders," she said.

A longtime administrator for a private Massachusetts speech-evaluation clinic that is paid by Social Security to conduct independent testing on some SSI applicants described speech delay as a much overused category. The administrator, who asked to remain anonymous for fear of jeopardizing the clinic's relationship with Social Security, said there has been an uptick in such claims in the last five years and was shocked that many children with relatively moderate speech issues end up getting approved by the government for benefits.

But some early childhood specialists say that federal authorities should be commended for trying to identify problems early on in preschoolers, and that they can understand the desire to help vulnerable families with limited cash. Sheila Smith, director of early childhood for the National Center for Children in Poverty in New York City, said all the best therapeutic services may not work well "if Mom can't put dinner on the table."

A mixed blessing

When the SSI approval letter comes in the mail, many indigent parents have no idea exactly why their child was approved. All they know is that their child is in line for a steady stream of cash benefits, a fact that can end up being a mixed blessing.

Shauna Lougee was euphoric when she learned in July, only two months after she applied, that her 2-year-old son's case was approved, though she is not clear if it was because of speech delay or autism. Her boy, Gavin, was awarded \$700 a month, plus \$1,400 in back payments from the date of her original application.

"I can move out and get my kids new beds!" exclaimed the mother of two, minutes after hearing the news this summer.

But as the months passed, she said, she began worrying that this extra money was sapping her motivation to get a job or more education. Gavin's SSI check is her family's second: Lougee has been receiving \$600 a month through the adult SSI disability program based on her diagnosis of depression.

"SSI sucks you in," she said. "Most people get lazy. I just don't want to become lazy."

Lougee, 25, came of age during the emotionally charged debates over welfare overhaul in the 1990s. She said she agrees with the critics of the old welfare system who described receiving benefit checks as a hard habit to crack. She said she aspires to be a strong mother who can support her own family, feel good about her life, and be a good role model for her children.

"I'm trying — no, I mean, I'm going, I'm going to go back to school," said Lougee, who hopes to become an electrician's assistant.

She said she hopes 2-year-old Gavin makes significant strides in his speech. And though she has heard that disability reviews are rare, she said she does not care if Social Security takes away his benefits as a result.

“If they give the money easily, I figure they can take it back easily, too,” she said.

Gavin’s speech therapist, Jackie Neiman of the May Center in West Springfield, said some children’s speech problems improve rapidly, particularly those whose delay is largely due to a lack of verbal stimulation at home. But other cases are more difficult and improve slowly, even with regular therapy. She is hopeful that Gavin, who shows signs of being autistic, will improve steadily.

“We’re certainly hoping he’s not the same kid you’ll see at age 4,” Neiman said.

Roxanne Roman, who rents a \$455-a-month apartment in downtown Holyoke for herself and her two sons, said Alfonso’s speech has improved considerably. He can now speak in full sentences, though he still has to be reminded to speak slowly enough to be understood. During his last year at the Head Start center in Holyoke, however, he became particularly disruptive and impulsive, and a doctor diagnosed him with ADHD. The boy is now on two psychotropic medications.

Some parents, Roman said, end up having mixed feelings when their children’s problems begin to go away, fearing this means that the disability checks may disappear, too. Roman, who said she does not want to become dependent on the money, has recently taken a temporary job at a nearby factory. Her shift begins at 3 a.m.

Mostly, she said, she wants her son to get better, and never intends to tell him the reason behind the monthly SSI checks in their mailbox.

“I don’t want him to grow up thinking he’s disabled,” she said.

Patricia Wen can be reached at wen@globe.com

© Copyright 2010 Globe Newspaper Company.

A cruel dilemma for those on the cusp of adult life

By Patricia Wen

Globe Staff / December 14, 2010

Last of three parts

HOLYOKE — Bianca Martinez is 15 and has a dream, to work someday as an animation artist, preferably in Japan, a country she has been fixated on for years.

But for now the idea of getting any kind of paid job, even at the Holyoke Mall, where many of her teenage friends work, worries her because of what she might lose: Her \$600-a-month federal disability check, which represents more than half her family's income.

“That’s why I’m not working this summer,” said Martinez, a freshman at Holyoke High School who is being treated for ADHD and depression. “If I work and I get a certain amount, then they’ll take money away from my mom. She needs it. I don’t want my mom’s money to go down.”

Tens of thousands of teenagers who receive disability checks through the \$10 billion federal Supplemental Security Income face this same painful dilemma: They are old enough to accept part-time jobs, but they worry that the extra income will be detected by the government and cause their benefits to be docked or terminated. In many cases, their indigent families have depended on the income for years.

This is, a Globe review has found, another disturbing unintended side effect of a program built on good intentions — targeting aid to the disabled children of America’s poorest households. Teens whose diagnosis has meant vital income for their families feel pressure to stay away from work — even if they are capable of being employed — and rue missing out on a vital part of growing up, the proving ground for the adult workplace.

It is a problem the Social Security Administration, which runs SSI, is concerned about but does not know how to resolve. And it is a problem that many of the dozens of poor families interviewed by the Globe are remarkably candid about, even as it pains them to speak of it.

Milly Cruz, Bianca’s mother, was laid off earlier this year from her job as a special education aide. She acknowledged that Bianca’s benefit, in addition to her oldest daughter’s \$500-a-month SSI check for ADHD and speech delays, has sustained the family for more than a decade. She is not happy about it, but she also does not see an easy way out.

“It makes me sad that my daughter worries about me and the income, the SSI check,” she said while sitting in her daughter’s bedroom, filled with Japanese artwork. “She’s got enough issues. She shouldn’t have to worry about the budget in the family, or my income problems.”

According to Social Security Administration rules, a teenager’s first \$85 a month in earned income can be kept without affecting SSI benefits; beyond that, however, the federal agency deducts \$1 for every \$2 earned, which many teens see as a virtual 50 percent tax rate. If a family’s total household income passes certain thresholds, SSI checks can be cut off entirely. Such Social Security scrutiny, triggered by income, can also lead to a more serious consequence: a determination that a teen is no longer disabled at all.

Youth job counselors and lawyers who handle disability cases say this work predicament runs deepest among teens who became eligible for SSI based on behavioral, learning, and mental disorders, the rapidly growing categories under which more than half of the children in the program now qualify for benefits. These teens are more likely than those with profound physical and congenital disabilities — such as Down syndrome, blindness or cerebral palsy— to take on the kind of part-time job that their classmates typically pursue.

“Most young people want to work,” said James Smith of the Vermont Division of Vocational Rehabilitation,

which received a grant from Social Security to help youth on SSI acquire job skills. “It’s often their parents who complain about their child working. These families are poor, and they depend on the SSI check.”

Smith said renewed efforts are needed to help these young people acquire the employment skills — and personal confidence — to become financially independent. The alternative is easy to fall into but dreary, indeed.

“It’s sad to go a lifetime on SSI,” Smith said. “It’s a poverty program.”

‘A reason not to work’

It is a prospect that fills Kris Long with dread.

Since he was 16, Long has qualified for the children’s SSI program for his depression and bipolar illness. When he was a student at New Bedford High School, he recalled, he felt envious of peers who earned extra money by working at restaurants and stores. He says he did not work because he did not dare jeopardize his \$700-a-month SSI check, which was critical to his family.

“I heard that if I was working, my check would be reduced,” said Long, now 21, who grew up in this struggling port city. “It gave me a reason not to work.”

Just before Long’s 18th birthday, he requalified for the adult version of the SSI program, a transition that is often hard but wasn’t for him because he was able to convince Social Security of the severity of his disability.

Many teens are jolted by the reality that a disabled adult and a disabled child are very different people in the eyes of the Social Security Administration. Under the agency’s definitions, children are deemed disabled if they exhibit “marked and severe” impairments compared to their peers. The adult standard focuses only on an individual’s ability to hold a paying job or participate in “substantial gainful activity.”

As Michael Kelly, a Boston lawyer who specializes in SSI cases, bluntly put it, “Just because you have a learning disability doesn’t mean you can’t dig a hole.”

As a result, of all the teens who apply for adult SSI benefits just before their 18th birthday, four of every 10 are rejected — and the odds are worse for those with behavioral, learning, and mental disorders. Two of every three teens who qualified for SSI for those impairments are turned down for adult benefits.

Though Long feels fortunate to have cleared the hurdle, he says he has mixed emotions about it. He eagerly awaits the check’s arrival in his mailbox each month but is wary of becoming addicted to the benefit. Living in a New Bedford studio, he takes the bus to computer courses at Bristol Community College and dreams of earning good money as a video game designer. But giving up the familiar SSI check, he acknowledged, will not be easy because he sees the work world as highly unpredictable, especially for someone with a thin resume, like his, and mental struggles that require medication.

“It does feel like a trap,” he said. “You depend on the check, and you don’t want to let go. Sometimes I’m afraid to lose the check. It’s attached to me.”

A habit of mind

The sense of dependence on SSI checks, for children and for their families, can creep up slowly.

Children who qualify at a very young age often go years before connecting their medical and therapy visits with the money their parents depend on. Many parents say they avoid telling their children, not wanting them to feel stigmatized by a “disability” label. Some also put it off in the hopeful belief that the child’s impairment, and the family’s need for the money they get as a result of it, will pass.

But when these children reach adolescence, the reality is hard to miss. The family’s financial struggles are as plain to see as the comforting constant of the SSI check.

A private psychologist who conducts hundreds of independent disability evaluations each year for the Social Security Administration, and who asked not to be named because he is not authorized to speak about his cases, said children who grow up on SSI often cannot see themselves ever living outside the system. It is a habit of mind that can have serious implications.

“They develop an identity as being disabled,” he said.

Some teens even come to see their monthly disability checks as partly their money; their parents give them a portion to spend like an allowance. Social Security officials say such a practice is acceptable if the allowance is spent on necessary expenses specific to the disabled child.

One South Boston High School student, sitting among friends on a bench at the Mary Ellen McCormack housing project, said his parents give him \$100 out of each monthly SSI check. The student, who asked not to be named because he wanted to keep his involvement with the disability program private, said he has been receiving SSI checks for years due to ADHD and learning disabilities. Of the \$100 he receives, he says, “I can do anything I want with it.”

His friend, Shamus Flaherty, 21, said he grew up in the South Boston housing projects seeing many adults and children qualify for SSI based on emotional or behavioral issues, none of which seemed serious to him. Despite periods of homelessness and being laid off, Flaherty said, he hopes never to have those checks become part of his life.

“There are people who absolutely need it — they’re blind, they’re deaf,” he said. “And then there’s the other half. They should have more serious screening.”

A fear of becoming dependent on the check is why Eliseo Ramirez, a 15-year-old New Bedford High School student, has virtually begged his mother not to apply for SSI benefits for him, even after a state social worker suggested she do so. His mother said the social worker predicted quick approval of benefits, given Eliseo’s behavioral and learning problems.

In the past year, the teenager was diagnosed with ADHD and depression, and placed on medications. He also spent some time in a residential facility for behaviorally troubled youth after he began skipping school, experimenting with drugs, and getting into fights.

Eliseo said he has seen troubled classmates qualify for SSI, then lose their ambition to get part-time jobs or strive for better things in their lives. Some, he said, have drifted into the underworld of drug dealing because they didn’t want any above-board income.

Ramirez said he is turning his life around and wants to earn his own way in life, possibly as a professional boxer or singer.

“I don’t want to depend on the check,” said Ramirez, sitting on the back steps of a city housing project. “I’ll be lazy, hanging around the house.”

Busy hanging laundry on a clothesline behind her apartment, Eliseo’s mother, Yolanda Rosa, 40, said that she respects his views, but that money is tight. The mother of four said she receives about \$1,300 a month in welfare, food stamps, and child support, which is not enough to cover all of the bills. She said she had worked briefly as a \$7.25-an-hour seamstress in a factory but quit because she believed the bosses exploited the workers.

“I feel sad,” she said about the remote possibility that she will still apply for SSI for Eliseo. “But I need the money.”

She knows the risks. Her extended family includes some teenagers on SSI who work very little, if at all, and simply are, as she put it, “used to getting checks.”

A destructive dependence

Top Social Security officials, in an interview at the agency's headquarters just outside Baltimore, said they also worry that the SSI program for children may have the unintended effect of sapping teenagers' motivation to enter the workforce.

"The question becomes whether it increases the chances the child will see himself forever dependent on government programs of some sort," said David Rust, deputy commissioner in the agency's Office of Retirement and Disability Policy. "It's very destructive to the child and child's well-being."

In one of the agency's own studies, researchers found evidence suggesting that many teens, in the year before turning 17, apparently try to work less or to conceal income, perhaps to boost their chances of qualifying for the adult SSI program. The study found that at a time when the number of children on SSI is growing rapidly, the percentage of teens reporting an annual income of \$250 or more had declined, down from 24 percent in 2000 to 16 percent in 2005.

Researchers speculated that this decline may be related to a deliberate effort to hold down reportable income and may be, in part, due to "a conscious effort to remain on SSI."

Federal officials have tried to address the problem by creating programs that could encourage teens to work. In one such program, for instance, any full-time student under age 22 is eligible, upon request, to earn up to \$6,600 a year, without facing reductions in their SSI check. But the program is not used much, because few families seem to know about it. So far, only 3 percent of those eligible have taken advantage of it.

The many benefits of SSI

On a sweltering August afternoon, outside a 300-unit New Bedford housing project, adults and children of all ages escaped the heat by relaxing on their back porches. Here, among the barbecue grills and parked bicycles, the term SSI is far from alien. Even two adolescent girls racing around the courtyard freely acknowledged they both receive SSI checks for their behavioral and learning disorders. Both take multiple psychotropic medications, and one, a 15-year-old, said she was particularly careful about the drugs during her recent pregnancy. As she played outside, her 4-month-old baby was napping in one of the units, watched over by the teen's mother.

Gathered around one set of concrete steps, a half-dozen young men — nearly all of whom were enrolled in the SSI program as children — chatted among themselves about how they make ends meet.

"It takes too long to get a job!" said a 19-year-old New Bedford High School senior, who had been on SSI since he was a preschooler diagnosed with ADHD and asthma.

The student said that he was rejected for SSI benefits after turning 18, and that he is appealing. The young man, who asked to remain unidentified to avoid adversely affecting his appeal, said his dream is to go to college and become a lawyer. But for now he cannot even get a job at McDonald's or Walmart because he was told he needed a high school diploma. At times, he said, he wonders if the SSI checks will ultimately be a more reliable source of income than a low-level job. After all, there is the nagging fear: "What if you're laid off?"

This student, like the other men in his group, said the benefits of the SSI checks go beyond their reliability. Qualifying for SSI means being instantly eligible for MassHealth, the state's health insurance plan for the poor. Many of the young men still live with their parents, so the maximum \$700 a month in SSI payments goes a long way toward covering extra expenses.

Some of the men are also fathers, who say that while work wages can be garnished for child support, the SSI check cannot.

David, a 23-year-old father of three, said he was tempted to stay on SSI but is now working a full-time \$9-an-hour job at a food distributor because he feels an obligation to pay his child support. If not for his sense of financial responsibility to his children, the man, who asked to be identified only by his first name, said he

would have tried to stay on SSI after turning 18. He had been receiving SSI for ADHD since his middle school days.

“I love free money,” he said, his work identification badge still attached to his clothes. “But I got kids to support.”

Still, he said, he is often jealous of friends who can do as they please every day, sustained, however meagerly, by the hundreds of dollars from their disability checks.

Another man in the group, William Keefe, 36, who qualified for SSI as a child, based on ADHD and learning disorders, said he feels fortunate to still receive his disability checks. Keefe, who grew up in Quincy, said he was easily passed from one class to another in school, without learning the basics. Even in 10th grade, he said, he still “couldn’t read.” While he briefly fell off the SSI rolls after turning 18 and worked part-time in landscaping, he requalified for SSI in his early 20s. He said his mental disabilities prevent him from working.

“And if I get a job, is it worth it,” he said, “if it gives me a McDonald’s job?”

‘I’m less likely to work’

Sherri Nichols, director of programs in the New Bedford office at My Turn, a drop-out prevention program, struggles to make sure teenagers on SSI avoid defaulting into a life of disability checks as they make the transition to adulthood. Her aim is to intervene just as these teenagers are “hitting this crossroads in their lives.”

Raya Umansky, a 17-year-old Salem girl, is among those at this transition point. She has struggled with ADHD, bipolar illness, and learning disabilities, but has no plans to quit her part-time \$8-an-hour job as a grocery store bagger.

“I love my job,” said Umansky, who hopes eventually to move up to a cashier’s job. “It’s fun. Sometimes you might have some grumpy customers, but they always smile when you say, ‘Thank you for coming.’”

Her mother, Meryl Umansky, said her daughter’s pay stubs were cited by the Social Security Administration as one of the reasons it suspended her family’s \$400-a-month federal disability checks this summer. Authorities said the teen’s \$80 a week, combined with her mother’s wages as a part-time swim instructor, put the family’s household income just above the allowable threshold. The mother said she has not told Raya about the latest suspension of the SSI check, because she is worried it might cause her daughter to feel guilty or affect her positive attitude about work.

“These kids don’t want to be dependent, but the system makes them dependent,” she said.

Sitting one summer afternoon outside the Brighton housing project where she lives, 16-year-old MayMay Martin — who has qualified for SSI payments based on ADHD, bipolar disorder, and learning problems since elementary school — is well versed in the role that teenage wages have on the benefit. Her older brother, now 21, also qualified for SSI, and she frequently overheard conversations about how his income affected his SSI check.

“I’m less likely to work,” she said near the project’s basketball courts. “I feel my mom needs the money to pay the rent.”

For that reason, she said, she does not plan to take a job anytime soon, even though last year she enjoyed her a temporary stint as a day-care assistant making \$326 every two weeks.

“I love working with kids,” she said.

Thinking ahead, she said she aspires to go to college, get a good job, and have an apartment of her own. But she also realizes that many adults, including her parents, managed to care for themselves and even raise a family on

disability checks, and she does not rule out that possibility.

“I might be on SSI,” she said. “Most of my family has had it for a while. I don’t know. To me, if I have it, I have it. If I don’t, I don’t.”

END OF SERIES

Patricia Wen can be reached at wen@globe.com

© Copyright 2010 Globe Newspaper Company.
