

Given one way and taken away in another

JESSIE

Jessie lives in Racine with her three children. She works hard to make a home for her family despite her disabling migraine headaches, and an accompanying nervous condition, which she has suffered from since childhood. She takes medication daily and is still experiences 2 or 3 severe episodes each week. Doctors advise her to be careful with her diet - avoid processed foods, eat certain fruits and vegetables - in order to minimize the onset of headaches. Jessie shakes her head and says, "It's hard to watch what you eat when you ain't got nothing!"

One of the most perplexing realities for Jessie is the lack of coordination in programs that are supposed to assist the parent who is disabled. "When they give to you one way, they take from you another way....My SSI [is] raised [from a cost of living adjustment], then my house rent [goes] up from the housing authority...and my food stamps go down."

When notice of termination of AFDC was sent to Jessie in November of 1997, she knew her family was headed for hard times. Jessie is not able to work outside the home, and she gets no child support. She has family in Racine and they all try to help each other. The loss of over \$300 a month in family income, however, was not replaceable. Jessie's oldest son, Robert, a college student, described it this way: "Things went out the window in late November '97 when [Mom] got the letter....It was Christmas. It was the wrong time to do this."

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Jessie is behind in her bills now, and she sometimes borrows money at a high rate of interest to make it through the month. Money first goes for rent and food. They usually run short of food the last week of the month. She can't afford to rent musical instruments for her daughter or son, scrambles to pay fees for school field trips, and avoids shopping for needed clothes and shoes. She knows her kids are suffering as they try to keep up at school and maintain a sense of well-being.

Their Racine neighborhood has become a dangerous place to live. Jessie described recent murders, drive-by shootings, and other gang activities on nearby streets. She realizes that despite her desire to provide a safe home environment, without money, she cannot change her family's situation. She keeps her teenage kids inside when they get home from school.

Jessie wants her children to finish school and go to college. She knows that education and a good job are the best insurance for a good life. "It has been hard for [my mother], says Robert. "I'm helping my little brother and sister understand....They are having a tough time....The money's just not there." Jessie summed up her efforts in this way: "I try to talk to [my kids]...I don't do drugs, I don't drink, and I don't smoke....I tell them 'if you pick that up, you didn't get it from Mom!'...I [am] a good mother to my kids."



Empty stomachs

KATHLEEN

"I thought when you were disabled and you can't work that AFDC would keep coming [for the children], ... We couldn't go through another year like this..."

Kathleen confesses. "I'm hoping that the cuts don't last forever.... There are 5,300 families that are in my boat."

Kathleen lives in the northwestern community of Superior with her teenage son, Steven. She is disabled with a mental illness - paranoid schizophrenia. She had rheumatic fever as child and suffers from heart problems and other complications.



First hospitalized at eighteen, Kathleen did not begin to understand her illness until almost 30 years of age. She was married, working, and raising her two daughters when her mental illness finally overwhelmed her life. She began the life-

long challenge of developing a more stable life through self-awareness, family support, and medical intervention. Her current regime of medication works better than earlier trials, but there are times when her illness takes control. Her mother and friends stay in close contact to help monitor her condition.

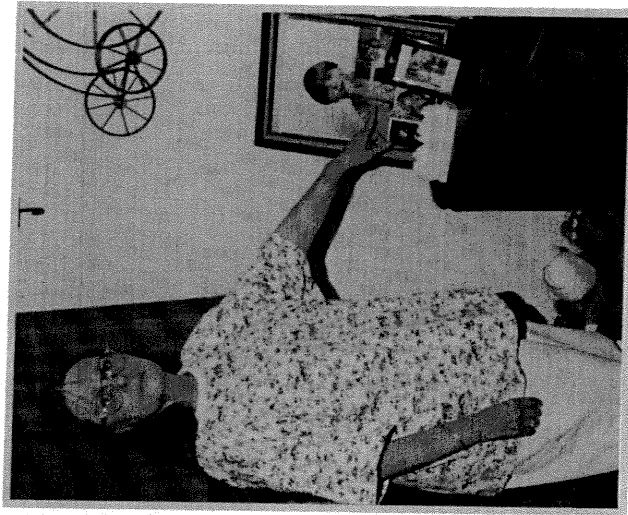
Kathleen worked as a receptionist, secretary, bookkeeper, employment counselor, apartment manager, and many other short-term jobs. As she got older, it became harder and harder to cope with her illness, maintain employment, and support herself and her newborn son. In 1985, Kathleen applied for disability benefits.

The termination of AFDC in January 1998 destroyed the fragile emotional and economic truce that Kathleen had carefully constructed for herself and her son. With her SSI benefits, AFDC for her son, and \$50 in child support from Steven's father, the two of them managed to have a place to live, food on the table, and clothes to wear. Kathleen estimated coming up about \$30 short at the end of each month before cuts, but with some juggling, she could pay most of her bills.

Since January, with \$200 less a month to cover expenses, they have been on a steady slide into debt and despair. "I thought when you were disabled and you can't work that AFDC would keep coming [for the children]," Kathleen says in disbelief. The cuts hit the food budget immediately. Kathleen's son detests the food they get from the local food pantry. There are seldom frozen pizzas or burritos for dinner. The refrigerator is often empty. During an argument a few months ago, Steven told his mother, "Mom, you know why I get so angry? When my stomach's empty!"

Kathleen worries most about Steven's future. He has lost all interest in school, comes in late most evenings, and got caught selling a stolen bike last spring. She says he bought a bike for \$10 and sold it for \$50. He bought soda and pizza with the money. Steven finds odd jobs when he can, but opportunity is limited because he is only fifteen and has only a bike for transportation. Katherine can't afford to replace the busted tire on his bicycle. Winter weather in Superior is severe and she knows Steven needs a warm coat and boots.

"We couldn't go through another year like this..." Kathleen confesses. "I'm hoping that the cuts don't last forever....There [are] 5,300 families that are in my boat."



Family network gets them through

LAURA

Within hours of the birth of her daughter, Laura had a stroke. She was eighteen and in a coma due to complications from the childbirth. As she slowly began her recovery, Laura was stricken with seizures, memory loss, and neurological impairment. Over the next two years with rehabilitation and family support, she regained her eyesight and hearing and learned to walk and talk again.

From the trauma of the stroke, she suffered permanent damage to her heart and cognitive impairment.

Laura lives in the rural northeastern community of Casco in a modest two bedroom home with her six-year-old daughter, Ashley, and her two-year-old son, Grayson. Laura's mother, Sally, lives nearby, oversees the family's financial affairs, and keeps close watch on Laura and the children.

Laura's family took care of baby Ashley while she was in the hospital and working in rehabilitation. They lived with family members until Laura was ready to live on her own and arrangements for the family's housing were complete.

Laura receives SSI as her basic income. Grayson's father lives in the home and commutes to Green Bay for his job. He contributes to family income as



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Laura's struggle for recovery against all odds and her determination to make a safe, peaceful home for her children.

much as he can. Laura gets no child support for Ashley. In the past she received \$240 in AFDC for Ashley. Laura and her mother are working to restore additional support for Ashley, but Laura gets no benefits for her daughter for now. She gets



limited help with food from the WIC and food stamp programs. Both children are eligible for medical assistance.

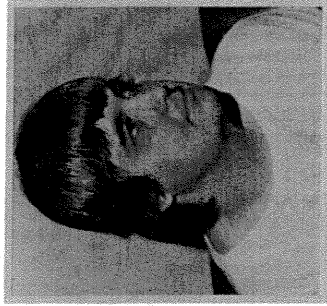
There is not enough money to care for the children and pay all of the bills. Laura will not spend money on herself because her kids come first. Local community services are generous to the family. The food pantry usually can get them through the lean days at the end of the month. A local clothing program also assists the family, especially Laura.

Laura's home is her haven. Laura spends her days taking care of her children and cleaning her home. Her mother arranged a mortgage that Laura pays directly to the bank to ensure that Laura and the children had a decent place to live nearby their family. Laura, her sister, and her mother provide mutual support for each other. Sally has great respect for Laura's courage to recover and determination to be a good mother.

Recent changes in benefit programs eliminated 30% of the family's income. Because of an incredible family support network, Laura and her two children have a place to live. Laura's partner is working and contributing to the overhead. Sally knows that Laura is doing all she can to care for the children. However, Sally worries about the future, knowing that she may not always be around to protect them when times get rough. The government cuts seem cruel in the face of this struggle for recovery against all odds and Laura's determination to make a safe, peaceful home for her children.

Lack of benefits coordination

LORETTA



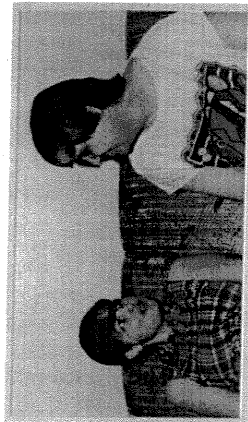
Loretta knew from her swelling joints and aching body that she was seriously afflicted before she was diagnosed with several forms of arthritis in 1992. She tried to continue working as a caretaker for the elderly and studying to be a nurse's aide. In her late thirties, her strength and stamina gone, Loretta had no choice but to apply for SSI disability. Despite a strict regime of medication and surgeries, her muscles continue to atrophy and cramp and her joints swell. In the last two years, her digestive system has given out and she fights chronic infections in her weakened body.

"I'm pretty sick and I'm just trying to make it from day to day...and it's really hard as it is and then when the state takes away our money like that it makes it even harder." A first floor apartment in the southwestern corner of the Green Bay area became home to Loretta and her youngest daughter, Becky, about three years ago. They had moved about once a year since Becky was in elementary school in search of safe, affordable housing. There is limited public transportation in this suburb, so Loretta walks about a mile to the grocery store to buy the fresh-only foods she must eat on her special, limited diet. A medical van is usually available for transportation to her doctors in Marshfield.

"When the government more or less put everybody in this AFDC box ... they didn't stop to figure that SSI parents are different than any other AFDC person," ... We can't work, we can't get loans, we can't better ourselves in any fashion.... Now we are just sitting here surviving... It is very hard to live this way."

Before AFDC was cut in January, Loretta and her daughter had learned to live simply and comfortably on \$800 a month. Without AFDC for Becky, Loretta's disability benefit, intended by the federal government for her basic living needs, must support the two of them. There is not enough money anymore. Loretta must choose between food for her family or over the counter medication to ease her constant indigestion.

In addition, the lack of coordination of benefits between various government programs places this family's finances on a constant roller coaster. Loretta describes how first with minimum notice the government took away \$240 in AFDC for Becky's support. Their subsidized rent and food stamps were adjusted, but their overall benefit income was significantly reduced. The caretaker supplement of \$77 a month partially restored their losses, but \$20 of the supplement would be required for a rent adjustment and their food stamps benefit would be lowered by \$20. In reality, the \$77 supplement was only \$37 for the family's cash income. The small increase in the supplement to \$100 last the summer was met with a caution by Loretta who expects there will not be much left for Becky in the end.



Becky is angry and frustrated. She is a seventeen-year-old high school senior who likes school and immerses herself in its activities. She can't afford other recreation. However, Becky must constantly choose between whether to buy food, clothes, or school supplies for herself. She knows a part time job would give the family extra money, but she is fearful it would jeopardize her mother's benefits. This unpredictable impact is a disturbing disincentive in SSI families. Becky would like to go to college, but she knows she will have to work instead to support herself and her mother.

"When the government more or less put everybody in this AFDC box...they didn't stop to figure that SSI parents are different than any other AFDC person," Loretta explains. "...We can't work, we can't get loans, we can't better ourselves in any fashion....Now we are just sitting here surviving....It is very hard to live this way."

Fighting for her life

MARY

"Who figured out that a disabled parent can raise a child on \$77 a month. That is less than it would cost to place my children in foster homes..."

"I apply repeatedly for work programs but no one will give a woman in a wheelchair who cannot breathe without oxygen, and has frequent bouts of difficulty breathing with oxygen, a chance."

Two years ago, Mary had a bilateral lung transplant. She could no longer breathe on her own due to damage from childhood asthma and emphysema. Now Mary's body is rejecting the transplanted lungs and she grows weaker by the day. She must use oxygen 24-hours-a-day in order to breathe. Yet Mary's greatest dilemma is her struggle to decide who will care for her two teenage daughters when she succumbs to her disease.



Mary has been a single parent in Green Bay since shortly after her youngest daughter was born. She cannot work outside the home. She has supported her family with her SSI benefits and AFDC. Although her medical emergencies often strained their limited resources, they had learned how to live modestly and get by. When AFDC was terminated at the end of 1997, the family's monthly income dropped by \$300. As she fights for her life, she must now search for a home she can afford to rent, alternate paying her bills, limit her daughters' school activities, and somehow, keep her faith that they will survive.

Mary uses a personal care attendant to assist her daily activities, housekeeping, and doctors' appointments. A physical therapist visits twice a week to ensure her mobility and treat shoulder damage from carrying her oxygen tank. When she goes to the doctor in Madison, a friend will drive her car and the long trip is exhausting. Neighbors sometimes provide meals.



On the impact of losing AFDC for her children, Mary declares: "How can this be? Who figured out that a disabled parent can raise a child on [\$100] per month. That is less than it would cost to place my children in foster homes and it is assumed that the foster home has at least one working parent. I would be glad to work, even at a minimum wage job. I apply repeatedly for work programs but no one will give a woman in a wheelchair who can not breathe without oxygen, and has frequent bouts of difficulty breathing with oxygen, a chance."

The girls' father has not paid child support since the divorce over ten years ago. Mary cooperated with Child Enforcement and even paid out of her own pocket to serve papers on him. Officials promised to finally get support for the girls, but they never enforced the court order. "It's just a lot of paperwork...and nothing happens afterwards," Mary says with conviction. "So, we sit again with nothing. They take away the AFDC and say the fathers will pay the child support. Then let's get after it. Let's do something about it. We're sitting with nothing."

Mary worries about her daughters' futures. They are good students with ambitions to get an education and a good job. Their loss of AFDC means instability - moving, changing schools, struggling for life's necessities - that exacerbates the impact of a mother's terminal illness. Mary writes to her daughters in a journal every day; she made a video for them. "I love my kids and I guess I just don't want them to forget me or forget that I love them." Finally, Mary added, "Whoever made this decision [to eliminate AFDC for parents who are disabled]...really did not think about us."

Doing the best she can

MELODY

*Melody shares pictures
with Netty Diaz, her
supported
parenting
worker.
support
from
community
agencies is*



*vital for Melody
and her son.*

Melody described the time she had to wait from Friday until Monday to get her 5-year-old son's broken foot put in a cast. When Marthew was first injured, she carried him to an emergency room and they put on a splint. The cast would have to wait until Melody could find transportation across town to the HMO's clinic. She had no money for bus or cab fare. When her supported parenting worker came over on Monday, they rushed to the clinic.

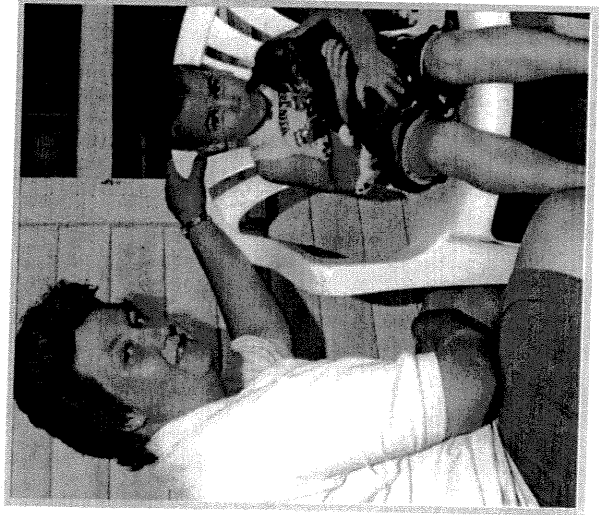
Without access to a phone or transportation, many ordinary incidents become emergencies for Melody. Since AFDC was ended and a reduced supplement offered to disabled parents, Melody's family has faced many changes. She moved from a three bedroom to a one bedroom apartment. She gave away many possessions she could not fit in her small apartment. Her son has the bedroom; she sleeps on the couch. Melody is still behind on her utility bills.

Melody is cognitively disabled. She describes her disability as mental retardation, a nervous condition, and asthma. She finished high school, although she functions at about a sixth grade level. She can read, but understands best if she reads aloud.

When she was younger, Melody worked as a live-in companion for an elderly woman. She was not successful at factory work because she got too nervous and shaky. The staff at the Division of Vocational Rehabilitation worked with Melody last year to explore training as a nurse's aid. When she gets Matthew settled in school, she wants to go back for training and a job.

Melody strives to be a good parent. The support she receives from many community agencies allows her to remain in her own home caring for her younger son. In addition to her supported parenting counselor, she works with child welfare, home-maker services, and medical doctors. She is learning more about budgeting her income, buying nutritious low cost food, and positive parenting techniques. Her youngest son attended a summer enrichment program, which prepared him to enter kindergarten this fall.

When her mother died unexpectedly four years ago, Melody was devastated by the loss of her mother's love and support. After years of struggling to keep her oldest son at home, he was recently placed in a treatment facility in another city. Her sister lives in town and they try to help each other in hard times.



At present, Melody focuses her energy on taking care of her son. She believes he feels stress from all these changes and their life on the edge. With the cut in benefits, she always worries how they will make it through the month. She says she has a lot to worry about, but she is doing the best she can.

Broken promises

PAO

Pao and her daughters grow food in their garden during summer months. When they must buy all their food, they cannot pay for other necessities.



Pao is the widow of a Hmong soldier killed while fighting along with US troops in Southeast Asia. Her two young sons died the following year. It was not safe to return to Laos at the end of the Vietnam

War, so she fled to Thailand with other Hmong refugees. After 13 years in refugee camps, Pao was convinced to come to America where she was told her family would be protected and cared for by the US government. Pao and her three daughters immigrated to the United States in 1988.

Pao's eyesight was severely damaged by chemical spraying in the jungles of Laos. One of her legs is partially paralyzed following an illness while in a refugee camp. She speaks only her native Hmong language. She cannot read or write English.

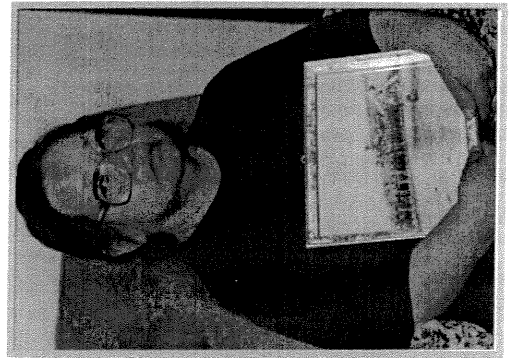
Recent cuts in benefits have devastated Pao and her family. When she arrived in America, she was reunited with a niece, and their families have worked together to make a home in this country. She applied for assistance and was granted SSI because of her disabilities. To support her daughters, she received food stamps, AFDC, and medical assistance. With careful budgeting and mutual family support, they were able to live a safe and decent life.

The federal government in July 1996 terminated food stamps for legal aliens. Pao was shocked to learn that Hmong people were not considered worthy to receive assistance for food. She was told because they were not citizens they would have to feed themselves. How could this be. Pao wondered? Refugee workers had told her that her family would be taken care of in America. They worked hard to grow food in their garden during summer months. They could buy food, but could not pay for other necessities. It was very hard on her family.

The state government in January 1998 terminated the benefits of the AFDC program and replaced it with Welfare to Work. However, Pao could not work and was not eligible for any benefits of the W-2 program. The loss of food stamps and AFDC cut family income by over 50%. She now had less than \$600 in disability benefits to support her family. Pao talks tearfully about the tragedies of her life - the death of her husband and sons in the war, 13 years of starvation, sickness, and abuse in refugee camps, the loss of her homeland and culture, and now starvation in America. She cannot understand why this is happening.

Pao's three teenage daughters speak Hmong and English. They are good students and they want to be productive Americans. Pao's daughters and niece interpret the letters and phone calls from government workers to try to help her understand what is happening. When she goes to the public offices to talk with workers, there is usually a Hmong interpreter. Nevertheless, there is no explanation for benefit cuts that can satisfy Pao.

The caretaker supplements replaced about half of the AFDC benefits for the girls and probably prevented the loss of their home. News that food stamps benefits would be restored to Hmong families was met with guarded relief. The expression of grief and disappointment on Pao's face will not fade quickly. Promises were made to her and other Hmong families by the government. Those promises were broken.



Safety and stability lost

STACEY

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When AFDC benefits were terminated in January of 1998, Stacey and her five-year-old son, Theo, could no longer afford their one bedroom apartment in a safe neighborhood in Madison. After living with friends for a short period of time, they eventually moved into public housing. It is their most affordable housing option, but Stacey knows it is an area with a reputation for violence and crime. Stacey worries about her son's safety now. "This instability is not healthy mentally for [my son] and I realize that and this moving we've had to do is not healthy for him....He has nothing to hold on to."

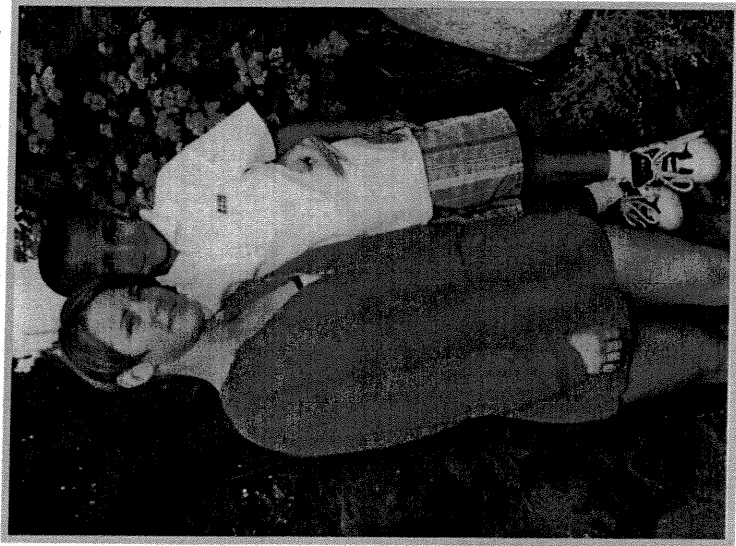
Stacey is disabled by the effects of seizures and chronic fatigue. "I look completely normal and I function and everything is fine. So [the medical community] said 'It's all in your head.' I wish they could be in my head when things start to change... because there is nothing I can do about it," Stacey confessed. She was 23 before a medical diagnosis was achieved. Stacey is young, ambitious, and wants to work. When a seizure happens, usually 2 to 4 times each day, Stacey has difficulty thinking coherently, she feels dizzy, her speech slurs, and she loses muscle control. Her best response is to lay down, sleep for about an hour, and wake slowly. In a work-place, this is difficult behavior for employers to tolerate. Consequently, her employment has been sporadic.

When Social Security determined that Stacey's medical condition prevented her from holding down a job, the SSI benefits gave them a financial safety net. "I'm not thrilled about getting Social Security," Stacey admits, "not because of the amount of money...but the stigma that goes with being 'disabled'....I want to be productive..., but because of [my diseases] it's extremely hard for me to be productive. People look at me and say 'you look completely normal' and I would like to be....it's frustrating to try to survive."

In January, Stacey's income fell by 45%. Once again, this family of two must overcome the stress and changes that such a loss of income brings.

Because of seizures, Stacey must be careful with her diet and she knows that her son will thrive only if his nutrition is adequate. Stacey sums up the food dilemma by saying, "Coupons, food pantry, and food stamps are stretched, but when we run out of food, that's it....There's just never enough."

With such limited dollars, some monthly bills can't be paid. Stacey's car was stolen in March and there is little hope of replacing it. When her son started first grade this fall, she had no money for new clothes. Stacey trades haircuts, housecleaning, and sometimes food with friends. Watching every penny is stressful for her. "It's frustrating because I can't afford to give him things that would give him an edge....I'm very concerned with how he's going to turn out later. I want him to be more than what we are now. I want him to succeed....He's such a good child and he's so bright."



Health destroyed by tainted water

TAMMY

*"Living in my
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In 1993, Tammy was working as a nursing assistant in a county hospital. She was supporting her 5-year-old daughter and successfully managing her asthma, the chronic illness that had challenged her every breath for over a decade. Then she unknowingly ingested the deadly cryptosporidium virus from Milwaukee's tainted water supply. The virus assaulted her body, and through no fault of her own, her health was critically and permanently damaged.

To ease lung distress and avoid surgery, high doses of prednisone were prescribed to keep her alive. However, the side effects have greatly compromised her health. Complications include glaucoma, diabetes, migraines, sleep apnea, allergies, reflux disease, fragile bones, and a weakened immune system. She takes dozens of medications each day to stay alive.

Tammy is no longer able to venture outside her home and find employment to support herself and her daughter. She gets no child support from her daughter's father. SSI and AFDC were the financial benefits that allowed them to live a modest, ordinary life. With careful planning, Tammy and her daughter managed to meet their basic needs each month.

Elimination of AFDC by the State of Wisconsin in late 1997 was a devastating blow to Tammy's financial survival. Even with a cost of living adjustment in SSI and caretaker supplement for her daughter, each

month Tammy is over \$100 short of the money needed to take care of her family. The abrupt loss of AFDC and lack of alternative resources for planning added to Tammy's confusion, distress, and hopelessness.

The support of extended family is critical to Tammy's survival. "Living in my parent's home keeps us off the streets." She and her daughter now live in Wauwatosa with Tammy's mother. She contributes \$200 each month for household expenses and tries to cover groceries and medical co-payments with the remainder of her disability benefits. Her mother regularly supplies money or food to get them through the month. Her sisters pitch in to lend emotional and financial support whenever they can. Tammy borrows from her mother, pays her back the next month, and then borrows again. Since the cut in benefits, there is never enough money to meet their basic needs.



In thinking about her daughter's future, Tammy is overwhelmed by her fragile health and not being there to care for her. "You have to have a college education to get a decent job nowadays," says Tammy. "I want her to become something. At this rate, she will never get there. I'm saving pennies. Pennies don't add up that quick."

That missing \$100 a month paid for school clothes, supplies and activities, kept the car running, bought enough groceries to feed them for the month, and allowed them to live in a place of their own. With her health problems increasing, Tammy finds herself choosing whether to spend \$50 for co-payments for medicine and doctors' visits or food each month. "They need to be more supportive of people with disabilities. Give more than taking. They are continuously taking and we can't make it. I don't know where I would be without my family," concludes Tammy.

Facing homelessness with twins

TYONNA

"I love them....and I want to be able to take care of my kids myself....I can do the things that most parents do for their kids," she said proudly.

"I'm gonna have to have a little help."

"Miracle babies" is how Tyonna describes her 18-month-old twin girls who were born on Mothers' Day. Disabled by juvenile rheumatoid arthritis since age three, Tyonna was surprised to learn she was pregnant with twins! Due to complications, she spent the last two months in the hospital before they were successfully delivered.



"I still can't believe that they are here," she said, smiling and shaking her head.

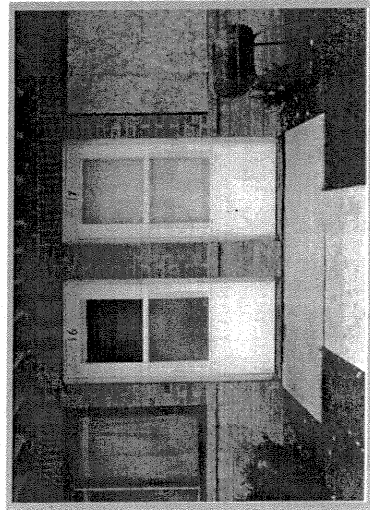
Tyonna cannot walk and is in constant pain. Surgical intervention started when she was sixteen. Both hips have been replaced and many joints surgically fused. Her arms and legs are frozen in awkward positions and her muscles weakened by the disease that continually attacks her joints and bones. The medications prescribed to provide relief from pain and inflammation produce serious, debilitating side effects.

In December 1997, Tyonna learned that AFDC would be terminated for parents who were disabled and unemployed. Homelessness was the immediate crisis Tyonna faced. A few months earlier the twins' father had abandoned them, and Tyonna knew her income alone, SSI benefits, would not cover their

necessities of rent and food. Her grandmother saved them from the shelter when she offered a room in her home for several couple of months.

Tyonna eventually found a small, dilapidated, two-bedroom apartment in a dangerous neighborhood in north Milwaukee to call home. Violence, robberies, and drug dealing are a constant threat. She gets no housing assistance and the apartment is not wheelchair accessible. Tyonna needs a personal care attendant to assist her to use the bathroom, get dressed, cook meals, move about the home, and help take care of the twins. Tyonna is searching for safe housing that allows her to fully use her wheelchair and regain more independence. Without special transportation and money, she knows this quest will take time.

For now, she struggles to feed her family and maintain her fragile health. When the \$160 a month in food stamps and WIC vouchers for the girls are gone, there is little money to get them through the last weeks of the month. Tyonna often eats only when taking her medication in order to stretch their food supplies. Transportation that accommodates her wheelchair is hard to schedule and expensive to use.



Tyonna wants to learn to work with computers. Although finding training and employment that accommodate her limitations has eluded her, she said, "I want to go back to school and show [my babies] that I am doing something [to provide for them]."

These "miracle babies" keep Tyonna hopping and working for a better future against incredible odds. Affordable, accessible

housing and transportation, job training and employment, medical care, and adequate benefits to care for her children would allow Tyonna an important opportunity. "I love them...and I want to be able to take care of my kids myself...I can do the things that most parents do for their kids," she said proudly. "I'm gonna have to have a little help."

Pushed to the edge of survival

JOAN & JOHN

"Why are disabled parents put in the same category as W-2 parents? ... My husband and I are not able to raise our daughter on \$77 a month... [Former AFDC benefits of] \$240 a month isn't a lot to raise a child on either, but we were at least able to live with a bit of dignity.... I feel as though we have been put in jeopardy with our daughter's health... This never should have happened."

Joan and John are frustrated and angry. The impact of the loss of AFDC has pushed their family to the edge of survival. Joan asks, "Why are disabled parents put in the same category as W-2 parents and their children? My husband and I are not able to raise our daughter on [\$100] a month...I don't think I am asking for the world. [Former AFDC benefits of] \$240 a month isn't a lot to raise a child on either, but we were at least able to live with a bit of dignity... I feel as though we have been put in jeopardy with our daughter's health... This never should have happened."

The Stenersons live in Wisconsin Rapids with their eight-year-old daughter. After severe head trauma from a car accident in the 70's, John never recovered to a level that would allow his return to the workforce. Joan has suffered from a schizophrenic disorder since the age of 23. While medication controls her symptoms, she finds that she cannot manage the stress of the workplace. Joan and John married in 1988. They both receive SSI due to their disabilities.

The greatest challenge for this family has been how to provide adequate nourishment for their daughter and themselves following the loss of \$150 in monthly benefits - the difference in AFDC and the current Caretaker Supplement payment. Joan has squeezed their food budget to the limit, using what she calls "negative challenges" to maximize their groceries.



She adds powdered milk to a gallon of 1% milk to enhance its nutrition for their daughter. When she shops on the first of the month, she buys only the cheapest produce, fruit when on sale, and wheat bread for fiber. Despite limited portions for everyone, the amount of food they can afford is usually consumed in the first half of the month. The local food pantry will allow one visit per month providing enough canned goods to get them through another 3-4 days. The last week of the month is always a struggle.

“Women and children first. I always went by that,” offered John. “I would budget myself to one meal a day. But now it’s gotten so bad that isn’t even enough.” He must tell his daughter, “No you can’t have a piece of bread. That’s got to last you until tonight.”

To the advice of workers to go on a budget, they reply that there’s nothing left to budget. When the \$77 went to \$100, food stamps decreased \$9 and rent increased. “That \$150 from AFDC made the difference in our life,” said Joan. They have no reserves. Like other SSI parents they juggle paying their bills and see no way to catch up. John does janitorial work from time to time, but must be mindful not to exceed the limit that would jeopardize the family’s current benefits.

“Watching our daughter grow is the best part of life,” John added. Now they struggle to feed her, can’t pay for any recreation, and have no gas for transportation. Joan tries to keep a good attitude, but admits some days it’s impossible. “I worry a lot. Like John said before, [these cuts] should never have happened. I can’t believe it did. I can’t believe they let it go this far. In three to five years, what’s [our daughter’s] health going to be like?” she asks.

Working jeopardizes medical benefits

MARY ELLEN

Mary Ellen Hall and her two youngest daughters moved to Oshkosh three years ago after she fled another part of the state to escape an abusive marriage. She worked at many jobs while caring for her four daughters, but now is disabled from degenerative arthritis, back injuries, and loss of sight in one eye. She has difficulty walking, standing for long periods, or any continuous action.

To help keep the family afloat, she recently found work two to three days a week at a retail outlet that is willing to accommodate her need for frequent breaks. The system's "catch-22" means her family's benefits will be cut on average \$1 for every \$2 she earns. By the time rent goes up, food stamps go down, and gas and clothes for work are purchased, their actual income may even be less. She must be careful with her hours worked so she doesn't risk losing medical benefits for the family.

The cuts in benefits have been hard on the family. They find incredible support in each other and from their new community. Mary Ellen is hopeful that once the government understands the hardship loss of benefits brought to the children of disabled parents, policies and programs will be re-evaluated.



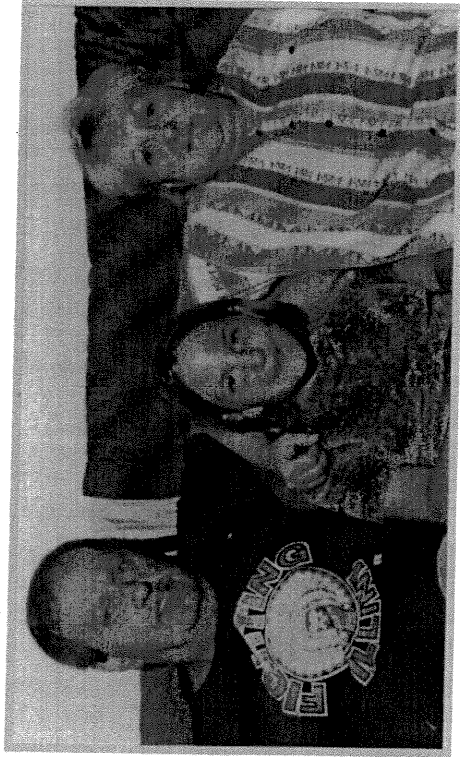
Courtney needs a future

COLIN & CHRIS

Colin and Chris Cameron live in Marshfield with their 10-year-old daughter, Courtney. They describe themselves as older parents of a “surprise child who keeps them going.”

When Chris was sixteen, she was critically injured in a collision with a drunk driver. Her chronic pain from the trauma, limited mobility, and continuing surgeries prevent her from working. Although Colin worked all of his life, in his forties he battles with disability from Multiple Sclerosis and heart disease.

They both receive SSI but are having great difficulty meeting their daughter’s needs since AFDC benefits were cut in January. They just can’t understand the priorities of government that result in benefits being taken from children whose parents are disabled. They say they have lost all their dignity in their struggles with the government, but they want to fight for their daughter’s future.



Overcoming a traumatic past

TED

Ted fights for his life through the disturbing effects of post-traumatic stress syndrome every day. Depression, which hangs heavy on his mind, is broken regularly by severe panic attacks. The past haunts Ted. He was raised in a troubled, violent family. His mother died when he was nine. Ted describes a childhood and youth punctuated with physical and emotional abuse, alcohol and drugs, runaway traumas, and incarceration. Now he manages his sanity with the help of a therapist and medications, the love of his children and a brother, and a few close friends. His fragile mental health prevents any steady work effort.

Ted lives outside Chippewa Falls with his three children. He began receiving SSI for his disability and AFDC and food

stamps to support his children three years ago. While the food budget has always been tight, the cut in AFDC benefits in 1998 left no money to buy school clothes or supplies for the kids or to cover utilities for the home. He is losing phone service because he can't keep ahead of the charges from month to month. The heating bill from last winter has not been paid yet and a new winter season is fast approaching.

The cuts in benefits have greatly impacted the children and threatened Ted's ability to make a home for his family. Everybody's who is effected [by cuts] has to juggle bills, says Ted. There is no way possible anybody could go through the winter time on disability and make all their payments and not owe [utilities] come spring.



Lack of affordable, accessible transportation

PATTI

Three years ago Patti was shot in the chest and back. One of the bullets hit her spine and left her paralyzed from the chest down. Her children were 6 weeks, one, two, and four years old. An act of domestic violence changed their lives forever.

Patti's extended family lives near them in Racine and they all pitch in to keep the family routine going. A cousin lives with the family, helps care for Patti and the kids, and contributes to household expenses. They have become a pretty good parenting team, according to Patti, but she doesn't know what she will do if her cousin ever has to leave their family.



1998 AFDC cuts seriously compromised this family's resources, as well as Patti's ability to parent her young foursome. Moving about in a wheelchair out in the world is always challenging and often impossible. Neighbors and family help, but taxis, paratransit, or the bus are too expensive for everyday activities. They need an accessible van for transportation.

Patti hopes to return to work as a teacher when her children are all in school.

Without a specially-equipped vehicle, it is impossible to take the children to daycare, attend classes needed for re-certification, or eventually go back to work. With termination of AFDC, there is barely enough money from SSI and C-Supp for family essentials, so having that van is only a dream.

FAMILIES IN POVERTY

Parents with Disabilities and their Children

*A report on the effect of
Wisconsin's Welfare Reform Program on
families headed by a parent who receives SSI because of a disability*

Caroline Hoffman & Amy Fisher
Wisconsin Council on Developmental Disabilities
PO Box 7851, 600 Williamson Street
Madison, WI 53707-7851
608/266-7826

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Caroline Hoffman can be reached at WCDD, 600 Williamson Street, PO Box 7851, Madison, WI 53707-7851, (608) 266-7826, (608) 267-3906 FAX or hoffmcp@dhts.state.wi.us

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Other publications in the WCDD Welfare Reform and Disabilities Series:
Fragile Families: Personal Stories about the Impact of Welfare Reform in Wisconsin on Families Headed by Parents with Severe Disabilities by Rosa Garner and Judy Pierotti. Available January 1999.
Background data from the WCDD Parents on SSI Initiative. Available December 1998.

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 - To the volunteer interviewers who shared their time with families
 - To the parents on SSI who contacted the WCDD to share their personal stories
- Thank you to all of the people who helped the Wisconsin Council on Developmental Disabilities gain a better understanding of the needs of families with a parent who has a disability:

Families in Poverty: Parents with Disabilities and Their Children

November 1998

Executive Summary

While having a low income and caring for children can be a challenge for any parent, the challenge is compounded when the parent has a disability and is unable to increase the family's income. This report presents a picture of families in crisis - parents who are struggling to meet their children's basic needs.

- There are 5,941 Wisconsin families headed by a parent with a severe disability who are caring for 11,452 dependent children who have been affected by the ending of AFDC and the start of the W-2 and Caretaker Supplement programs.

- Prior to W-2, low-income parents with severe disabilities received Supplemental Security Income (SSI) for themselves and a child-only AFDC grant for their dependent children. W-2 replaced the AFDC program. Since W-2 is a work-based program, it could not require work from adults on SSI who have been deemed unable to work. The replacement for AFDC for families headed by a parent on SSI is a new program, the Caretaker Supplement (C-Supp) Program.

- SSI is a federally and state funded program which provides a cash benefit to the elderly and disabled. To be eligible for SSI, people must be too disabled to be gainfully employed and lack income and resources. The maximum total 1998 SSI monthly grant to an individual is \$577.78/month, and to a couple, if both are disabled, is \$873.05. An individual's grant may be less if they have other income.
- The Caretaker Supplement provides a monthly grant to support the dependent children of parents on SSI. From January through June 1998, the grant was \$77/month per child. On July 1, 1998, the grant was raised to \$100/month per child.

COMPARISON OF AFDC AND CARETAKER SUPPLEMENT

Number of Children	Maximum AFDC Payment (before 1/1/98)	Caretaker Supplement 1/1/98 To 6/30/98	Caretaker Supplement After 7/1/98	Income change from AFDC to Caretaker Supplement (at \$100/mo)
1	\$249	\$ 77	\$100	60% reduction
2	\$440	\$154	\$200	55% reduction
3	\$517	\$231	\$300	42% reduction
4	\$617	\$308	\$400	35% reduction
5	\$709	\$385	\$500	30% reduction

- Families in Poverty: Parents with Disabilities and Their Children* presents the findings of the survey of 2,242 parents, interviews with 374 parents, and the letters and comments received from over 300 parents.
- The families on the Caretaker Supplement program reside in every county of the state with a majority living in Milwaukee County. A single female parent who is non-white, above the age of 30, and caring for 1 or 2 children heads most of the families. The parents have a wide range of disabling conditions with the majority having a mental disorder, physical disability, or chronic illness.
- The disparity between income and expenses was poignantly expressed in letters sent to the Wisconsin Council on Developmental Disabilities. Families described being unable to pay their rent, feed their family, or pay basic living expenses (ex. clothes, shoes, toothpaste). Many parents wrote that they felt they were unable to do anything for their children, they felt they were being punished for their disabilities, and that their constant worries was affecting their health.
- 80% of the parents interviewed said they would like to work at some type of job. There are a number of barriers that prevent parents on SSI from working. The barriers include the severity of the disability, SSI work disincentives, exclusion from W-2 employment services, lack of access to childcare assistance, and the lack of employment opportunities.
- The programs established to help the families—SSI, Caretaker Supplement, food stamps, housing assistance, child support—often conflict with one another. A gain of income in one program often results in a reduction in income from another program. The result is that many families have an inadequate dependable monthly income.
- Parents reported being unable to pay the rent and utilities bill. A Dane County survey of parents on SSI reported that 32% were headed toward a housing transition because they were unable to pay the rent. 77% of the parents interviewed had been living in their current residence for less than 5 years.
- 60% of the parents reported that they could not afford to buy enough food for their families on their current income. Although 73% of the parents were on the food stamp program, the food stamps were insufficient to meet their family's food needs. Parents wrote of the basic items that they needed that food stamps can't buy (ex. diapers).
- More than two-thirds of the parents interviewed reported that they could not afford to clothe their family on their current income. 30% said that their housing was not warm in the winter.
- The drop in income with the start of the Caretaker Supplement Program has placed the families at risk for losing their housing and for being unable to provide the basic necessities for their children.

FAMILIES IN POVERTY: PARENTS WITH DISABILITIES AND THEIR CHILDREN

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I am writing to let you know how things are going and to give you my new address.
I moved into a smaller apt in June. I could no longer maintain my other apt. Hopefully I will be getting Section 8 soon. I applied for it in May. Because of the changes in AFDC the decrease has devastated me, my family and most of my hopes.
I will have the same phone number. But I don't even have a long distance or my line because I get behind. I have a bank line. I am not even able to call my brother who lives in New York with a father. It is the 19th of the month and I literally have 78¢ to my name. And my checking acct has \$1.45 in it. My \$120.00 in food stamps are gone. I do have food in the fridge. Thank God. But we will be without milk by the 21st and I must have no money until the 1st of September.
I haven't even seen my son at all this month because I have no money to even get him much less entertain him. I have a doctor's apt. I am even. The only reason I am able to go is they are allowing me to postdate my check. I gave up counseling. I couldn't afford the 2.00 co-pay.

8-19-92

Dear World,

I am kind of not making
 it. I have no money to get my
 daughter any school clothes. I
 have had to sell even the littlest
 things to make it. I've hobbid
 my baby's pram bank to do
 laundry.
 My husband who is createrated
 has sent me money every month
 to pay off my bills from my
 car repairs.
 Do they have any idea how
 much the extra \$18.00 I use to
 get tired. help. I get \$17.78
 a month. I pay \$405 a month
 rent. That isn't including gas,
 electric, phone or food. I do
 have cable because I live in
 Wauquon. There is no hupston
 way out here. It's not forget
 personal care items, cleaning
 supplies, laundry supplies and
 laundry gas. (Clothes, shoes, hair
 cuts, doctors visits (co-pays), mid
 gas for car, school fees, school
 supplies, toilet paper, toiletry, tissues,
 aspirin, medications not covered by MH,
 vitamins or any and everything else.
 Keep the idea of artthainment.
 I suggest from your division, ADD,
 and chore back pain and migraines,
 the financial pressure and dragging
 me down further and further.
 Why don't the people behind the
 change try to live on what I
 have and pay what I do out and
 see if they would make some
 changes. It's not to mean slow
 when it doesn't affect them personally

Xincerely
 Xincerely

FAMILIES IN POVERTY: PARENTS WITH DISABILITIES AND THEIR CHILDREN I. INTRODUCTION

With the advent of welfare reform in Wisconsin, 5,941 families caring for 11,452 children* have faced a severe drop in income. The families are headed by a parent who has a severe long-term physical or mental disability that prevents him/her from being gainfully employed, and who has limited income and resources. Because of their disability, the parent receives a monthly Supplemental Security Income (SSI) payment of \$577.78/month for an individual or \$873.05 for two parents, if they both have disabilities. (1998 amount)

Prior to the end of AFDC, the parents had been receiving SSI for themselves and a child-only AFDC grant for their dependent children. Under Wisconsin's welfare replacement program, Wisconsin Works (W-2), the families were placed in a new program called Caretaker Supplement (C-Supp). The Caretaker Supplement program reduced the monthly grant for dependent children in a family with two children by 55% from the grant level provided by AFDC. This paper presents a portrait of families with parents who have a severe disability and how the end of AFDC has affected them.

The Wisconsin Council on Developmental Disabilities (WCDD), a federally funded agency responsible for planning and advocating for people with disabilities, has been working to modify welfare reform policies so that they address the special needs of people who have disabilities. Concern for the well being of low-income families headed by a parent(s) who has a severe long term disability led the Wisconsin Council on Developmental Disabilities to fund a number of projects as part of the Parents on SSI Initiative. The purpose of the Parents on SSI Initiative is to gain a greater understanding of the life circumstances of low-income families headed by a parent with a disability, to promote self-advocacy, to improve the delivery of services, and to promote legislative initiatives that address the needs identified by the families.

THE WCDD PARENTS ON SSI INITIATIVE

Developing social programs to respond to the needs of families is impossible without an understanding of the families themselves. In 1996, when the Caretaker Supplement was first proposed within the W-2 legislation, almost no data were available on the families. This led the Wisconsin Council on Developmental Disabilities to begin the Parents on SSI Initiative. The Initiative includes a number of different activities. This report summarizes the information gathered from:

* The total number of children is 13,385, but children who receive SSI for themselves were not eligible for AFDC.

A. STATEWIDE DATA ON FAMILIES PARTICIPATING IN THE CARETAKER SUPPLEMENT PROGRAM:

The Wisconsin Council on Developmental Disabilities requested data from the Department of Health and Family Services, Division on Supportive Living. A letter dated August 28, 1998 included data on the number of families receiving a caretaker supplement by county of residence, race, age, family size, number of children receiving a Caretaker Supplement, number of SSI children in Caretaker Supplement families, and the average food stamp benefit for Caretaker Supplement families.

B. PARENTS ON SSI SURVEY:

In late December 1997 and early January 1998, at the request of the WCDD, a two-page survey was sent to each of the approximately 5,300 families in which the parent had received SSI for themselves and AFDC for their children. The survey requested the county of residence; the sex, age and disability of the parents; the number and ages of the children; where the children lived; the number and relationship of any other adult living in the home; and the number and disability of any children who receive SSI. Space was provided for any additional comments that the parents wished to make. Parents had the option of providing WCDD with their name, address and phone number and also could indicate if they would like to participate in a phone interview.

Of the approximately 5,300 families thought to be eligible for a Caretaker Supplement in December 1997, 2,242 returned the WCDD survey. This is a return rate of 43% and much higher than had been expected by the Wisconsin Council on Developmental Disabilities. All 72 Wisconsin counties were represented.

C. PARENTS ON SSI INTERVIEW:

Of the surveys returned, 804 families (36%) offered to participate in a longer telephone interview. From March 1998 to June 1998, 374 families participated in a 30-45 minute telephone interview conducted by 87 mostly volunteer interviewers. Phone interviews were attempted with another 170 families but were not completed for various reasons.

D. VOICES OF PARENTS ON SSI.

The WCDD has heard from hundreds of parents who have written eloquently about the effect of the change in their family income for their dependent children. Many of their comments, stories and letters have been shared with decision-makers and others who can influence public policy. This paper includes the lessons learned from their letters as well as letters and quotes sent to the Wisconsin Council on Developmental Disabilities. Although the contents of the parent's comments have remained the same, some letters and quotes have been edited for spelling and grammar to increase their readability.

E. LIMITATIONS OF THE DATA

Whenever possible, statewide data is used. When statewide data is unavailable, information derived from the survey and the interviews is presented. It is important to remember that both the survey and the interview were voluntary and therefore are not representative of the entire population of parents on SSI. This limitation is especially important because of the lack of statewide data on the nature of the parent's disability. Confidentiality laws and incompatible computer systems prevent a statewide summary of the disabilities of parents participating in the Caretaker Supplement Program. Without understanding the disabilities that the parents have, it is difficult to develop appropriate social policies that adequately respond to their needs.

The WCDD survey and interviews may under represent those who have more serious disabilities or are the most sick; those who have cognitive disabilities or other disabilities that prohibit them from being able to read, write or understand the survey; those who are homeless or moving around from place to place; and those who are the most isolated.

The complete data from the WCDD Parents on SSI projects is available in a companion publication, *Background data from the WCDD Parents on SSI Initiative*.

To whom it concerns:

I am writing in regards to the AFDC drop the added \$300 for C-supp. I am a single mother of a 2-year old son. I am feeling screwed every direction I turn.

I suffer from depression & PTSD. I have been on SSI for 3 years. Luckily I am able to work 10-15 hours at a minimum job each week otherwise I would never be able to make it & receive no child support from my son's father as he is in prison & receive no food stamps because of my wages from work. Although I am able to work, I am still making less than what I had with my son's AFDC grant. But the more money I make, the more my SSI goes down, the more my rent goes up, & the ~~drop~~ cost of my childcare increases as well.

So I made cuts here & there until I was able to manage & still buy food & diapers. I got behind & eventually my electricity was shut off. Thankfully, Salvation Army was able to help me out. Now 5 months later, I find myself behind once again - we go to food pantries, we take orders for free meals, & shop for clothes at rummage sales. In order to make it this month, I had to have my phone shut off.

Although every penny helps, I feel this \$300 increase was a joke. Because of that income, my rent went up again. (I live in subsidized housing) I add

receive county assistance for my childcare while I'm at work. With the increase, I am paying more for my son to go to daycare. I have kept an emergency fund in my savings account & that has dwindled down to nothing.

It just doesn't make sense & I wonder daily how I am supposed to ever get ahead I did not choose to have a mental illness raise my son this way, but I feel I am being penalized for such. I look forward to the day I don't have to juggle my bills & we can go to a nice dinner.

There are parents who are not able to work to supplement some of that lost income who are far worse off than me. The government would be paying more for foster homes & shelters, because many families will become homeless & many loving parent will be unable to care for their children financially, thus proving them to be unfit parents. Hmm, I wonder why... They did not choose to be disabled!

I refuse to become a victim in this, but the only positive thing I can find in this situation is that my son will grow up to enjoy the simple pleasures in life: a bottle of bubbles, a walk in the park, & learning how to find something good in every difficult situation. We are making it, but I ~~am~~ am deeply saddened for those who aren't!!!

Sincerely,

II. PARENTS WITH DISABILITIES AND THE AID TO FAMILIES WITH DEPENDENT CHILDREN (AFDC) PROGRAM

For the past three years, the public, elected officials, and the media have focused attention on welfare reform. The specific focus has been on the Aid to Families with Dependent Children (AFDC) program. AFDC was created in 1935 and guaranteed a cash grant to help children whose parents could not financially support them. The cash grant was primarily based on family size. In addition to cash grants, most families enrolled in AFDC received other benefits such as Medicaid and food stamps for their children. For families headed by a parent who receives SSI for a disability the parent could receive an AFDC child only grant to support their dependent children.

The two programs, SSI and AFDC, worked together to provide cash assistance to support the families. Both programs required that the families have access to very little income and assets. For SSI eligibility, the parent had to have assets less than \$2,000 for a single person or \$3,000 for a married couple (not including a home or car). The parent could not have earnings greater than \$500/month. The AFDC formula for eligibility took into consideration family income, size and configuration.

The following table shows for a single parent family under the AFDC program, the estimated maximum monthly income of the parent's SSI, the children's AFDC, and the household's food stamps.

ESTIMATED AFDC INCOME

	One Child	Two Children	Three Children	Four Children
1997 Maximum SSI income for one adult	\$ 567.78	\$ 567.78	\$ 567.78	\$ 567.78
Maximum AFDC income for children	\$ 249.00	\$ 440.00	\$ 517.00	\$ 617.00
Estimated Maximum Food Stamp benefit	\$ 42.83	\$ 55.83	\$ 119.75	\$ 166.75
TOTAL MONTHLY INCOME	\$ 859.61	\$ 1,063.61	\$ 1,204.53	\$ 1,351.53
TOTAL ANNUAL INCOME	\$10,315.32	\$12,763.32	\$14,454.36	\$16,218.36

4-6-98

To whom it may concern,

I just received a news letter on W.C.D.D.

In there was a letter of a meeting on April 13th at 1:00 PM Parents speak out. I cannot get to Madison, but I want my voice heard. Please!!!

Before A.F.D.C. went out I was able to feed, clothe, house, meet all my 17 year old daughters needs, besides me. Even if we had \$8.50²⁸ with section 8 we made it every month.

I am physically disabled with arthritis in my muscles, joints, & tissues. Plus a bad digestion disease. I am on a special diet. And am very sick at times where I have to go in for treatments to relieve pain or to be able to eat again.

When A.F.D.C. went out we lost \$71. My rent ~~went~~ went up \$9.00, my food stamp went up to \$87.00 for one month then got cut to \$77.00 due to the \$72.00 grant given in place of A.F.D.C. Then section 8 raised our rent from \$134.00 to \$154.00 no reason given.

Due to my diet disease my daughter is given the \$77.00 for her food for the month. That leaves \$57.28 for rent, phone, electric, school needs, child needs

toiletries & whatever is left is my food money. Sometimes I get \$50.00 sometime \$30.00

For the month of April there is no money at all for my food. I will live on steamed rice, and herb-decat tea. If I join in on my daughters or turn to resources, I will become awful sick & have to go in for treatment we live in America! Life should not be this way!

The Physically Disabled are physically sick, we did not ask for diseases or injuries. We should not be forced below poverty. And we should not be punished & our families punished for our sickness.

A.F.D.C. should not of been taken away from the ~~disabled~~ physically disabled. we cant work, we cant borrow money, we are in a poverty prison.

Looks this month I paid for 2 field trips for my daughter's schooling now I dont eat well for 31 days. Just steamed rice. How healthy is this??

Give the Physically disabled there Full A.F.D.C. grants back! Release us from this poverty prison! We are Americans just like every body that is healthy. We have feelings & our families have feelings! We are not just numbers & ways to save us money.

III. THE BEGINNING OF THE CARETAKER SUPPLEMENT PROGRAM

With the passage of federal welfare reform legislation in August 1996, the AFDC program was eliminated and replaced with the Temporary Assistance to Needy Families (TANF) block grant. TANF allows states to design their own welfare program. Overlooked in the rush to pass legislation were families caring for either an adult or child with a severe disability. Although the federal legislation was silent on consideration of the unique needs of people with disabilities, all but three states held the families harmless in the transition from AFDC to TANF by not changing the monthly benefit amount.

Wisconsin, along with Idaho and West Virginia, decreased the monthly grant for dependent children of parents with disabilities. Because Wisconsin's welfare replacement program, W-2, is a work based program it could not require work from adults on SSI who had been deemed unable to work. The W-2 law excludes parents on SSI from participation in any of the W-2 activities. To replace AFDC for families headed by a parent with disability on SSI, the 1997 Wisconsin Act 27 established a new program, the Caretaker Supplement program (also known as the C-Supp program). The eligibility criteria for the Caretaker Supplement program are included in Appendix A.

The Caretaker Supplement program established the new monthly benefit at \$77 per dependent child. In mid-November of 1997, with only a six-week notification, families headed by a parent on SSI suddenly faced a significant decrease in their monthly grant to support their children. Although half of the estimated 6,000 families were told the change would occur on December 1, 1997, the startup date for all families was moved to January 1, 1998 because of concerns over the lack of advance notification.

"I think the decision to cut AFDC came too quick. I didn't have a chance to save up or change my living environment." (Milwaukee County)

"Two weeks before December 1997, I received a letter notifying me that AFDC benefits are ending. I would now be receiving something called C-Supp. My income for my daughter went from \$248.00 to \$77.00 a month. A decrease of \$171.00 a month. With a two week notice before the Christmas season, I went from trying to raise my daughter on \$8.00 a day, to just \$2.50 a day. How can anyone ever raise a child on \$2.50 a day? I am suppose to house, feed, cloth, care and entertain a child on \$2.50 a day? How? God forbid the thought that my daughter deserves the rights to the basics. Forget the extras of maybe once or twice a month being able to go out for a Happy Meal. Because that would use up her full allotment for the day. A Happy Meal. Not so happy anymore." (A single mother with a physical disability and mental disorder, with two children. Dodge County)

On July 1, 1998, advocacy efforts resulted in legislative action that increased the monthly benefit to \$100 per dependent child. This increase of \$23 was offset by a decrease in food stamps on the average of \$7.00 per month, leaving a net gain for the families of only \$16.00 per month.

The actual food stamp benefit a family receives depends on a complex formula that takes into consideration housing costs, household configuration and other income. The amount used in the above calculation is an estimate of the maximum a family could be eligible for. Although the reduction in income for many families was partially offset by an increase in food stamps, food stamps cannot be used to pay for rent, clothing, transportation or other living expenses. Nor are food stamps a reliable source of income since the amount varies from month to month to reflect changes in monthly income. Since there is usually a delay in modification to the food stamp benefit, a parent may have a reduced food stamp benefit in the same month they have limited additional income.

One Child	Two Children	Three Children	Four Children	1997 Maximum SSI income for one adult	\$ 567.78	\$ 567.78	\$ 567.78	\$ 567.78
				Caretaker Supplement for the children (as of 7/1/98)	\$ 100.00	\$ 200.00	\$ 300.00	\$ 400.00
				Estimated Maximum Food Stamp benefit ²	\$ 109.92	\$ 161.92	\$ 203.92	\$ 235.92
				TOTAL MONTHLY INCOME	\$ 777.70	\$ 929.70	\$ 1,071.70	\$ 1,203.70
				TOTAL ANNUAL INCOME	\$9,332.40	\$11,156.40	\$12,860.40	\$14,444.40

ESTIMATED CARETAKER SUPPLEMENT PROGRAM INCOME

The following table shows the estimated maximum monthly income of the parent's SSI, the children's Caretaker Supplement, and the household's food stamps for a single parent family.

Number of Children	Maximum AFDC Payment (before 1/1/98)	Caretaker Supplement 1/1/98 To 6/30/98	Caretaker Supplement After 7/1/98	Income change from AFDC to Caretaker Supplement (at \$100/mo)
1	\$249	\$ 77	\$100	60% reduction
2	\$440	\$154	\$200	55% reduction
3	\$517	\$231	\$300	42% reduction
4	\$617	\$308	\$400	35% reduction
5	\$709	\$385	\$500	30% reduction

COMPARISON OF AFDC AND CARETAKER SUPPLEMENT

The following table shows the comparison in monthly income between the AFDC program and the Caretaker Supplement program for families who have between one and five children.

"Your letter asks for comments on the impact of losing AFDC for my children and instead getting an increase in SSI of \$77 per month per child. How can this be? Who figured out that a disabled parent can raise a child on \$77 per month. That is less than it would cost to place my children in foster homes and it is assumed that the foster home has at least one working parent. I would be glad to work, even at a minimum wage job. I apply repeatedly for work programs but no one will give a woman in a wheelchair who can not breathe without oxygen, and has frequent bouts of difficulty breathing with oxygen, a chance. My daughters are 12 and 14 years. I am fortunate to have the experience of parenthood when I have been ill all of my life. I have been divorced since they were preschoolers. Their father has evaded the law and pays no support. What can \$77 a month buy for a teen? Even if I could obtain food for a family of three on the \$144 food stamps I can receive, food stamps can not buy: toothpaste, shampoo, toilet paper, dental floss, or sanitary napkins, shoe laces, school supplies, haircuts, bus fare, laundry soap, washer and dryer money etc. Clothes, even bought at thrift stores, cost at least \$15 a month per child. You can not buy underwear, socks, stockings at thrift stores.

Two dollars and fifty three cents a day per child, \$77 a month. That would hardly pay for lunch eaten at school each day. Fortunately there is free school lunch but that may be cut next. Do we have cable TV? No. Nintendo, Sega, Playstation? No. Do we eat out or see a movie? Not often. What about birthdays and Christmas, or don't children with a disabled parent need gifts? I am discouraged. AFDC still left me below the poverty level but I could scrimp by. \$77 dollars a month per child just doesn't make it.

Brown County is a generous place. There are food pantries and thrift shops and caring people. I am sure it is worse for people in big cities or where rents are high. The idea behind W2 was to put able bodied people to work. I would love to have an able body and work. Even disabled I have done volunteer work when well enough. If there was another working parent there would be an income. I can not be the only single mother with no other source of income and no ability to work. It is the children who are punished. If AFDC can disappear how long with the \$77 continue, how long food stamps? I read the economy is booming, inflation low, interest rates low and jobs available. This is for able bodied persons only.

Monthly: Financial List of Basic Needs for Both Girls:

Shampoo \$2.00
 Kotex \$2.00
 Toothpaste \$1.50
 Deodorant \$1.00
 Soap \$.75
 Laundry Soap \$3.00
 Toilet Paper \$1.50
 Kleenex, bandaids, first aid stuff \$2.00
 Cleaner-Windex, floor, Ajax, etc. \$4.00
 School Supplies \$5.00 (replacement glue, tablets, ring paper, pencils, backpacks, folders, colors, colored pencils)
 Calculators \$15.00 x 2 = \$30.00 (one time beginning of school year)
 Replacements-toothbrushes, combs, brushes, hair bows \$3.00
 Co-Pay Services \$3.00
 Both girls receive free hot lunch at school
 Total. \$58.75-\$30.00 (for calculators) = \$28.75
 With the new W2 program and no child support and being legally disabled, each girl would receive \$77.00 per month = \$154.00

Basic Replacement Clothes: Every six months
 12 pair replacement socks (per 6 months) \$20.00
 6 underwear (per 6 months) \$9.00
 2 pair school shoes @ \$12.00 each = \$20.00
 2 replacement sweats \$20.00
 4 T-shirts @ \$5.00 each = \$20.00
 1 dress for concerts/special occasions \$15.00 (from thrift store)
 4 pairs of jeans (off brands) \$60.00

= \$180.00

1 jacket (light weight) \$20.00
 1 winter coat (spread over two years) \$30.00 from used clothing store. \$60.00 total
 outer wear - not at goodwill or thrift store - hats, mittens, gloves, boots, scarves \$20.00

= \$70.00

basic replacement clothes \$180.00

+ \$70.00

\$250.00 per child

With this new program I figure \$77.00 per child divided by 30 days in a month = \$2.57 per day per child + with the food stamps we get they would each receive \$1.00 a day

The basic list of needs does not include any of the following items which I feel my girls need but usually do not get:

In any six month period:

Fannyhose (one pair per month @ \$1 pair)
 Hair cuts or perms (they never get) \$15

School field trips (\$3 to \$10 per trip) \$25 (not talking about the weekend or Washington DC trip)
 One summer activity per girl (baseball or soccer) \$20 each registration
 Baseball glove, soccer ball or whatever needs replacing \$10

Presents to each other and parent for birthdays \$10 per girl, \$5 per present = \$20
 Gift when invited to friends' birthday parties (@ \$5 gift) minimum \$20

Swimming suit (hard to find at thrift stores) \$15 each girl
 Snack to entertain friend at sleep over, pizza and soda (2 for each girl at \$10 each) \$40

Girls allowance (they work for it) \$5/week = \$40 month (they don't always get it, only when we have the money)

Vacations (occur only when gift from others)
 Extra shoes for child with foot orthotics which broke the last cheap shoes (2 extra pair per 6 mo. at Payless) \$20

Co-pay on foot orthotics \$2 per visit
 Over the counter emergency cough syrup, Nylenol, cough drops, etc. \$5-10

Church, collection Sunday and occasional events \$10
 Emergency clothing (Grandma's funeral, family wedding, etc.) \$40

Total approximately \$347 extra per six months for the two girls."

(A single mother who has a life threatening chronic illness raising two children, ages 12 and 14. Brown County.)

*Brown, Chippewa, Dane, Dodge, Douglas, Eau Claire, Fond du Lac, Jefferson, Kenosha, La Crosse, Manitowoc, Marathon, Marinette, Outagamie, Racine, Rock, Washington, Waukesha, Winnebago, and Wood

County of Residence	Percentage (number of Families)	Distribution of AFDC families ⁵
Milwaukee County	52% (3,063)	60%
Other Counties with a City of at least 10,000*	34% (2,007)	27%
Counties with no City of at least 10,000, and the Tribes	14% (871)	13%

GEOGRAPHIC DISTRIBUTION OF 5,941 FAMILIES

The Caretaker Supplement program affects families in every county of the state.⁴ Caretaker Supplement families reside in every county of the state, but follow the same pattern of residence as the former total AFDC population with a disproportionate number of families living in the city of Milwaukee. A map of Wisconsin on the following page displays the distribution of Caretaker Supplement families by county of residence.

B. GEOGRAPHIC DISTRIBUTION OF FAMILIES

Number of Wisconsin families receiving a Caretaker Supplement	5,941
Number of children eligible for a Caretaker Supplement	11,452
Number of children with disabilities on SSI	1,933
Total Number of children in Caretaker Supplement Families	13,385

The drop in income from AFDC to Caretaker Supplement affected over 13,000 Wisconsin children.³ This includes all the dependent children living in families receiving a Caretaker Supplement. Children who are on the SSI program themselves because of a severe disability are not eligible to receive a Caretaker Supplement payment. But since these children live in families receiving the Caretaker Supplement, they also are affected by the decrease in family income.

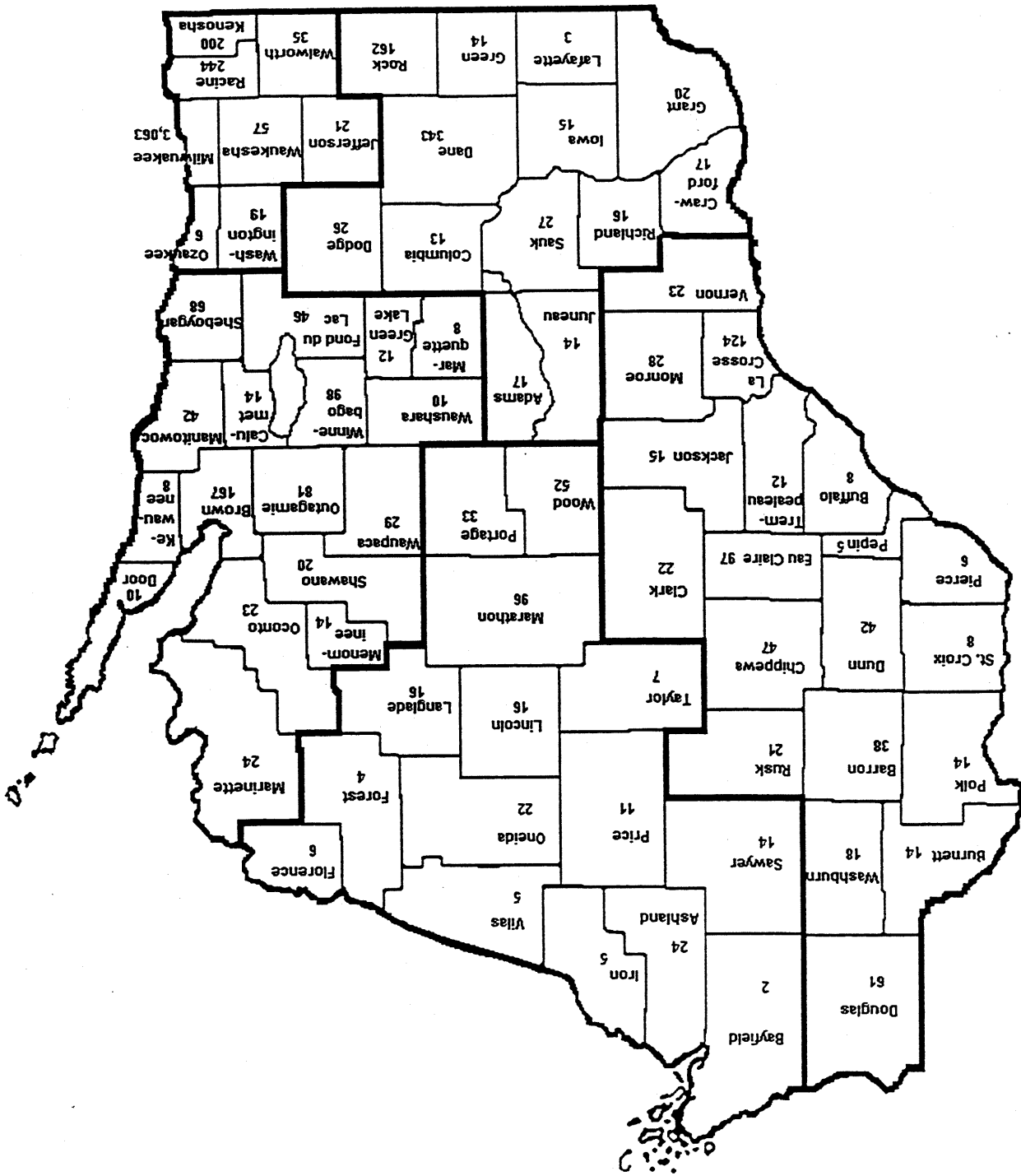
A. THE NUMBER OF FAMILIES AND CHILDREN AFFECTED BY THE CARETAKER SUPPLEMENT PROGRAM

The data in this section comes from: 1) the statewide data on 5,941 families provided by the Division of Supportive Living, Department of Health and Family Services; 2) the WCDD survey of 2,280 families and; 3) the WCDD interviews with 374 families.

IV. A PORTRAIT OF THE FAMILIES PARTICIPATING IN THE CARETAKER SUPPLEMENT PROGRAM

DISTRIBUTION BY COUNTY OF 5,941 CARETAKER SUPPLEMENT FAMILIES

Map prepared by the Wisconsin Council on Developmental Disabilities with data provided by the Department of Health and Family Services August 1998



C. DISABILITY OF THE PARENT

There is a wide range of disabling conditions represented by the parents on the Caretaker Supplement Program. All of the parents have met the SSI test and have been medically determined to have a severe long-term physical or mental impairment that is expected to prevent them from doing "substantial" work for a year or more, or who have a condition which is expected to result in death. Some conditions are from birth; others begin in childhood or later in adulthood. Some are from injuries, while others are life-threatening illnesses.

There is a strong correlation between poverty and disability. National studies indicate that "overall disability rates are more than twice as high for women aged 15-45 who live in poverty (17.1%) than for those who live above poverty (8%). Among poor women, a significantly higher proportion of those on AFDC (21%) had disabilities compared to those never on AFDC (12.4%)." ⁶

The WCDD survey asked parents to self-describe their disability based on the following categories:

PHYSICAL DISABILITY. Includes but is not limited to: Paraplegia/quadruplegia; physical limitations due to stroke/heart attack; spinal cord injuries and other injuries; and limitations due to diseases such as kidney failure, degenerative disorders, arthritis, or amputation;
CHRONIC MEDICAL ILLNESS OR DISEASE. Includes but is not limited to: Cancer; Diabetes; Heart Disease; Auto Immune Disease; Kidney Disease; Arthritis; or Lupus
NEUROLOGICAL DISORDERS. Includes but is not limited to: Seizure disorders/epilepsy; Brain Tumors; Multiple Sclerosis; Cerebral Palsy; and Amyotrophic Lateral Sclerosis (ALS)
MENTAL DISORDERS. Includes but is not limited to: Post traumatic stress syndrome; Schizophrenia and other psychotic disorders; Personality disorders; Affective disorders and Anxiety disorders
COGNITIVE IMPAIRMENTS. Includes but is not limited to: Autism; Cognitive Limitations including Mental Retardation and Learning Disabilities
VISUAL, HEARING, AND/OR SPEECH IMPAIRMENTS

Since the parents who responded to the WCDD survey were only given broad disability categories to choose between, it is possible that two parents with the same condition might pick different categories. For example, a parent who uses a wheelchair as a result of Multiple Sclerosis might have said they had a physical disability, a chronic illness or a neurological disorder. Or they might have said they had all three.

90% (329) of the parents interviewed were women. This is similar to the general AFDC population in which women head 90% of single parent households. Many women wrote of their partner leaving after they became disabled.

E. SEX, AGE AND RACE/ETHNICITY OF THE PARENTS

Length of Time on SSI	WCDD Interviews
Less than 1 year	4% (16)
1 year to 3 years	22% (82)
3-5 years	21% (77)
5-7 years	20% (75)
More than 7 years	32% (120)
Unknown	1% (3)

LENGTH OF TIME ON SSI OF 374 FAMILIES INTERVIEWED

The length of time parents reported being on SSI varied evenly between those who had recently been placed on SSI, to those who had been on a few years, and those who had been receiving it for a longer time period.

D. LENGTH OF TIME ON SSI

38% of the parents surveyed reported having more than one disability. In the smaller sample of families interviewed, 27% of parents who said they had a mental disorder also said they had at least one other disability, primarily a physical disability and/or a chronic illness.

*Percentages total more than 100% because some parents reported more than one disability.

Disability Category	WCDD Survey*
Mental Disorder	44% (993)
Physical Disability	40% (919)
Chronic Illness or Disease	19% (437)
Neurological Disorder	14% (307)
Cognitive Impairment	8% (266)
Visual Impairment	6% (171)
Hearing Impairment	6% (171)
Speech Impairment	4% (91)
Unknown	8% (182)

REPORTED DISABILITIES OF 2,280 FAMILIES SURVEYED

The most frequently reported disability was a mental disorder, followed by a physical disability. This is similar to 1994 national data that shows that the most commonly experienced self-reported disability in the AFDC adult population is mental illness and mental impairments.⁷

83% (1,892) of the parents responding to the WCDD survey were single parents. Since the statewide data listed the family size as including all adults and children living in the household, it cannot be used to determine the number of single parent households. For a two-parent household to be eligible for a Caretaker Supplement, both parents would have to receive SSI. If one parent receives SSI and the other does not, the family might be eligible for W-2.

F. FAMILY SIZE AND CONFIGURATION

Race/Ethnicity	Statewide Data
African-American	44% (2,624)
White	35% (2,062)
Asian, Southeast Asian and Pacific Islander	8% (479)
Hispanic	5% (298)
Native American	2% (90)
Other/unknown	7% (385)

RACE/ETHNICITY OF PARENTS IN 5,938 FAMILIES

Almost 60% of the Wisconsin Parents in the Caretaker Supplement program are non-White, primarily African-American. This is greatly disproportionate in comparison to the population of Wisconsin which is only 7.8% non-white with African-Americans representing 5% of the non-White population.⁹

Age	Statewide Data
Under 30 years	28% (1,681)
30-39 years	40% (2,351)
40-49 years	23% (1,368)
50+	9% (535)

AGE OF PARENTS IN 5,935 FAMILIES

The majority of the parents receiving a Caretaker Supplement are in their 30's or older. Unlike the general AFDC population where 52% of the recipients are below the age of 30, only 28% of the Caretaker Supplement parents are below 30 years of age. This is not surprising, since age is associated with increasing rates of disease and disability. A number of the chronic illnesses and neurological disorders identified in the SSI survey onset with greater frequency as women age (e.g. Multiple Sclerosis, Cancer, Lupus, and Arthritis).⁸

Age of Children	WCDD Survey
0-3 years	14% (422)
4-6 years	17% (531)
7-13 years	38% (1,168)
14-17 years	31% (942)
TOTAL	100% (3,063)

AGE OF CHILDREN IN 2,280 FAMILIES

In the families surveyed, a majority of the children are between seven and thirteen years old. This includes children with disabilities on SSI and those in the Caretaker Supplement program. Only 22% of the children are below the age of three. It is possible that parents caring for younger children did not respond to the WCDD survey.

G. AGES OF CHILDREN

*47 families had 9 or more children.

Family Size	Statewide Data
2 (single parent with 1 child)	25% (1,367)
3 (single parent with 2 children or 2 parents with 1 child)	29% (1,590)
4 (single parent with 3 children or 2 parents with 2 children)	21% (1,147)
5 or more household members	26% (1,400)*

FAMILY SIZE OF 5,504 FAMILIES

54% (2,957) of all Caretaker Supplement families live in a family that includes 3 or less members.¹⁰ The statewide data listed total family size and did not break the family down by children and adults. Therefore, in the statewide data, a family size of three could be an adult and two children or two adults and one child. The WCDD data showed that the average number of children in the households surveyed is 2.0.