

National Council on Disability

An Independent agency working with the President and Congress to increase the inclusion, independence, and empowerment of all Americans with Disabilities.

**TANF AND DISABILITY – IMPORTANCE OF SUPPORTS FOR
FAMILIES WITH DISABILITIES IN WELFARE REFORM****Position Paper****National Council on Disability****1331 F Street, NW, Suite 850****Washington, DC 20004****202-272-2004 Voice****202-272-2074 TTY****202-2720-2022 Fax****Lex Frieden, Chairperson****March 14, 2003****Introduction**

The Temporary Assistance for Needy Families (TANF) block grant, first created in 1996 to replace Aid to Families with Dependent Children (AFDC), was slated for reauthorization in 2002. Rather than undertaking the full reauthorization, Congress passed a short extension, which has since been extended to the end of June 2003. It is likely to be reauthorized by Congress in the next few months. As part of the reauthorization process, there have been many proposals to strengthen protections for parents and children with disabilities participating in TANF-funded programs. It is important that the law establish policies that reflect both the intention and desire of people with disabilities to work, and the reality that certain individuals may still have severe work limitations requiring long-term assistance.

While the TANF program is not specifically directed towards individuals with disabilities, research data indicate far-reaching effects of this program on people with disabilities. According to the General Accounting Office (GAO), a substantially higher proportion of TANF recipients reported having physical or mental impairments than did adults in the non-TANF population. In addition, many TANF families include a child with a disability. The work requirements and lifetime limits to benefits, which are key elements of welfare reform, pose special challenges for state and local TANF agencies in addressing the unique needs of families with a disability who are TANF beneficiaries.

People with disabilities often face multiple barriers to work. In addition to the barriers faced by most low income Americans as they attempt to work, such as inadequate transportation and limited opportunities to improve education and skills, people with disabilities must meet the specific challenges of their physical or mental impairment or health condition – often requiring assistive technology, access to accessible transportation, sign language interpreters, or personal care assistance, work place supports etc. in order to participate in programs designed to assist

them in finding work. When appropriate assessments of individual needs for reasonable accommodations are provided, people with disabilities are afforded equal opportunity for full participation, independent living, and economic stability.

Also facing extraordinary challenges are parents of children with disabilities, who are frequently unable to find or to afford a child care setting able or willing to handle the special needs of their children. These parents are often called upon to miss work to provide for these special needs, putting them at risk of incurring TANF sanctions. They are more likely than others to experience significant hardships when forced to leave the TANF program due to time limits.

While these additional challenges faced by people with disabilities may seem to paint a bleak picture, in fact, TANF creates a great opportunity to creatively design programs that can give parents with disabilities, and parents of children with disabilities, the training and support they need to secure and maintain employment. Some states and communities are already collaboratively working to help people with disabilities prepare for and sustain employment. Greater national emphasis on systemic collaboration and review of policies and legislation among federal, state, and local entities that bring consumers with disabilities to the table and begin dialogue and actions would serve to remove barriers and create real opportunities for people with disabilities to transition from welfare to work.

There have been many proposals to address the unique circumstances facing families on TANF who experience a disability (of the parent or the child or another family member). The most common of these proposals would require states to provide more comprehensive assessments of barriers to employment, including disabilities; provide states with greater flexibility in determining what counts as a work activity; bar states from sanctioning a family for non-compliance with a program rule if the TANF recipient or a family member has a barrier which prevents compliance and has not been provided with help in addressing that barrier; and provide funds for state-level advisory panels to consider ways in which a state can improve its TANF policies and procedures to better assist families who have barriers, including disabilities.

“Every American should have the opportunity to participate fully in society and engage in productive work. Unfortunately, millions of Americans with disabilities are locked out of the workplace because they are denied the tools and access necessary for success.” President George W. Bush, New Freedom Initiative at p. 18, (Feb. 2001), www.whitehouse.gov/news/freedominitiative/freedominitiative.html. For many people with disabilities, TANF, if appropriately designed, could provide the tools and access needed to unlock doors to opportunity, productivity, and economic self-sufficiency. This paper summarizes research about people with disabilities and TANF and some of the proposals being offered for consideration to improve how TANF-funded programs address the needs of families with a member with a disability. This paper concludes with the following recommendations from the National Council on Disability (NCD) for TANF reauthorization:

- Increase TANF and childcare funding;
- Ensure that parents with disabilities are screened, in a timely manner, with appropriate diagnostic tools;

- Prohibit states from sanctioning families until the state has taken steps to identify barriers, provided the family with assistance in meeting the rules; and modified rules, if necessary to address the parent's or child's disability so that the family can comply with TANF requirements;
- Provide states with flexibility in how they define countable work activities, including rehabilitation and participation in other activities that will help the parent to become work-ready, and how they determine the length of time a particular individual or family will need the specific services or treatment;
- Provide states with additional resources to train case workers and other staff who serve TANF recipients about issues unique to disabilities, including how to provide timely and effective screening, and how to identify programs, resources, and opportunities for collaborative community initiatives to achieve systemic improvements in services for people with disabilities;
- Create advisory panels at the state level to assist states in addressing the needs and barriers of people with disabilities;
- Facilitate access to continued Medicaid or other health coverage when recipients move from welfare to work;
- Assist states to better coordinate and provide services needed by children with disabilities and their families to address the multiple challenges facing parents and children with disabilities;
- Ensure that TANF programs and services comply with the Americans with Disabilities Act and Section 504 of the Rehabilitation Act.

Family Members with Disabilities and TANF – What We Know From the Research

Parents with disabilities.

Case #1

“DD is a 42 year-old woman with two children who has been trying to find appropriate work for the past five years. She has been receiving TANF ... She suffers from phlebitis, which causes severe pain without warning; her leg will become swelled and force her to rest, and on some days she cannot get out of bed at all. Extensive standing, walking, or other physical activity exacerbates the problem. She worked as a clerk for the Liquor Control Board for six months ..., but she was forced to quit because the job involved lifting boxes, and she was physically unable to perform the job's requirements. ... In 2001 she took the civil service exam as a clerk/typist, and she passed, but most recently she was #577 on the waiting list. Should her name come up, she will likely be further hindered by her lack of a General Equivalency Degree. DD is not considered exempt from TANF work requirements by DPW, and so she has had to look for work, and attend job readiness programs, rather than focus on a program which would enable her to earn her G.E.D. and improve her chances ... If she does find an appropriate job, she will need a boss who will grant her accommodations on days when she is unable to come to work. DD emphasizes that she is ready and willing to support her children, but after five years on TANF, despite her steady efforts to find work, she still does not have an education, the networking skills, or the medical support that would enable her to leave the welfare rolls. ...DPW referred her to a program in which she could obtain job training while also obtaining her GED, but on the second day of the program, her phlebitis acted up and she could not get out of bed. ... she cannot re-

enroll until she provides satisfactory proof ... but she cannot see a doctor [in time to keep the slot.] Eventually she may be able to re-enroll, but her sixty months on TANF will have long since run out. It is possible, though far from certain, that she could have obtained a full-time job by now, with the potential for raises and promotions, if she had been placed in a high-quality GED program at the outset of her time on TANF, if she had regular medical coverage and a steady relationship with a doctor who could provide ongoing treatment for phlebitis ... and if she had been placed in a good job training and placement program which helped line up interviews for appropriate clerical positions. Instead, DD encountered frustration, denials and inappropriate job offers.” Community Legal Services, Philadelphia, PA, Case Histories of Disabilities in TANF Families in Pennsylvania.

Case #2

“I am 28 years old and I have two children, ages five and seven. I have suffered from epilepsy ever since I was five, and I have unpredictable seizures that make it difficult to work. Although I can usually control the epilepsy with medication, when I am under a lot of stress I am more likely to experience seizures ... The father of my children was abusive to me, but in the summer of 1999 I escaped from the situation with the help of ... a domestic violence program. After leaving, I had a difficult time finding employment that would allow me to support my family ... I received TANF for a few months, but then my income from working in a laundromat was high enough that I was no longer eligible. Unfortunately, the laundromat manager had to let me go because I was having a lot of seizures, some of them at work ...that caused me to miss work. I turned to the state for help again ... I reapplied and thought I had completed the process. Around that time, I was also in intensive care for six days due to severe seizures. For that reason I missed an ... appointment. When I got home from the hospital, I was greeted with a letter saying that since I hadn’t shown up at the meeting I was not eligible for that month because I had not completed the application process. ... no TANF, no food stamps, and no help with childcare or other support services. I called my caseworker to explain that I had been hospitalized. ... For some reason, she questioned whether I had an appropriate referral to be hospitalized ... Even though my caseworker knew about my history of domestic violence and health problems, I was never told about good cause for exemptions.” Statement of a Maine mother from collection of Maine Equal Justice Partners.

There is now a substantial body of research that documents the nature and extent of physical and mental impairments of parents participating in TANF programs.¹ In a national study of TANF recipients, the General Accounting Office (GAO) found that 44 percent of TANF recipients had at least one physical or mental health impairment, three times higher than the rate of such impairments among adults not receiving TANF benefits.² In 1999, 38 percent of TANF

¹ For a more detailed discussion, see Eileen P. Sweeney, *Recent Studies Indicate that Many Parents Who are Current or Former Welfare Recipients Have Disabilities or Other Medical Conditions*, Center on Budget and Policy Priorities, February 2000, <http://www.cbpp.org/2-29-00wel.htm>. For a discussion of the most recent studies as well as the prevalence of other barriers to work in the TANF population, see Heidi Goldberg, *Improving TANF Program Outcomes for Families with Barriers to Employment*, Center on Budget and Policy Priorities, January 2002, <http://www.cbpp.org/1-22-02tanf3.htm>.

² U. S. General Accounting Office, *Welfare Reform: More Coordinated Federal Effort Could Help States and Localities Move TANF Recipients with Impairments Toward Employment*, GAO-02-37, October 2001, available at www.gao.gov.

recipients reported an impairment severe enough that the individual was unable or needed help to perform one or more activities, such as walking up a flight of stairs or keeping track of money and bills.³ In a second report, in July 2002, GAO found that recipients with impairments are half as likely to exit TANF as recipients without impairments. And, people with impairments are less likely than people without impairments to be employed after leaving TANF. Some who no longer receive TANF receive Supplemental Security Income benefits (SSI) while others do not.⁴ In 2002, the U.S. Department of Health and Human Services (HHS) Office of the Inspector General confirmed that high numbers of people with disabilities receive TANF.⁵

The Manpower Demonstration Research Corporation (MDRC), in another study measuring barriers among recipients in four large urban counties, found that nearly one-third of the non-working recipients studied reported having fair or poor health. Companion ethnographic interviews conducted by MDRC indicated that health problems were likely to be under-reported and under-rated in the survey and that the survey data did not accurately reflect the depth of severity of the problems that the mothers and children faced.⁶

There is a high incidence of mental impairments among parents who receive TANF. Based on its National Survey of American Families, the Urban Institute has reported that almost half of parents receiving TANF either said that they were in poor general health or scored low on a standard mental health scale. One-third either said that their health limits their ability to work or scored as having very poor mental health.⁷ Approximately one-quarter of those who have left welfare and are not working also have mental health impairments.⁸ Two studies, in Michigan and Utah, did in-depth diagnostic questioning of TANF recipients. The Michigan study focused on a sample of all TANF recipients in one urban county while the Utah study looked at those who had received welfare for at least three years. In Michigan, one-quarter experienced major or clinical depression, one-seventh had post-traumatic stress disorder, and about seven percent had general anxiety disorder. The results in Utah were similar: two-fifths had major or clinical depression, about one-seventh had post-traumatic stress disorder, and about seven percent had general anxiety disorder.⁹

³ *Id.*

⁴ U.S. General Accounting Office, *Welfare Reform: Outcomes for TANF Recipients with Impairments*, GAO-02-884, July 2002, available at <http://www.gao.gov>.

⁵ HHS Office of the Inspector General, *State Strategies for Working with Hard-to-Employ Recipients*, OEI-02-00-00630, July 2002, <http://oig.hhs.gov/oei/reports/oei-02-00-00630.pdf>.

⁶ Denise Polit, Andrew London, and John Martinez, *The Health of Poor Urban Women: Findings from the Project on Devolution and Urban Change*, Manpower Demonstration Research Corporation, May 2001, <http://www.mdrc.org/Reports2001/UC-HealthReport/UC-HealthRpt-Overview-2001.htm>. The study was conducted in four large urban counties: Cuyahoga County, Ohio; Los Angeles, California; Miami-Dade, Florida; and Philadelphia, Pennsylvania.

⁷ Sheila Zedlewski, *Work Activity and Obstacles to Work Among TANF Recipients*, Urban Institute, Series B, No. B-2, September 1999, <http://www.urban.org>.

⁸ Pamela J. Loprest, Sheila R. Zedlewski, *Current and Former Welfare Recipients: How Do They Differ?* Urban Institute, Discussion Paper 99-02, 1999, <http://www.urban.org>.

⁹ Sandra Danziger, Mary Corcoran, Sheldon Danziger, et al., *Barriers to the Employment of Welfare Recipients*, University of Michigan Poverty Research and Training Center, February 2000, <http://www.fordschool.umich.edu/poverty/wesappam.pdf>; Amanda Smith Barusch, Mary Jane Taylor, et al., *Understanding Families with Multiple Barriers to Self Sufficiency: Final Report*, University of Utah Social Research Institute, February 1999, <http://www.socwk.utah.edu/pdf/sri-final1.pdf>. See also, *Why Some Women Fail to Achieve*

Three states — Kansas, Washington, and Utah — undertook significant efforts to determine the extent of learning disabilities among current TANF recipients. The three studies found that somewhere between one-fifth and one-third of recipients have learning disabilities. The Washington study suggested that up to one-half may have learning disabilities.¹⁰ There also are significant numbers of parents who have physical disabilities. While less has been written about the nature and extent of recipients' physical impairments, it appears that about one-fifth of current TANF recipients have physical impairments that limit their ability to work. According to a 1999 report by the University of Utah Social Research Institute, among recipients who were not working, about one-third had physical problems. The Utah study suggests that the figure may be even higher among longer-term recipients.¹¹

Children with disabilities.

Case #3

"I have four children, three of whom have special needs ... my son, who is eight, has attention deficit hyperactivity disorder and has been diagnosed with oppositional defiant disorder ... my son, who is nine, is being studied for depression. My daughter, who is now six, has spina bifida, which is a serious problem that has required her to be catheterized several times a day ever since she was six months old. ... The worst part of my story is that when my daughter was from about six months until three, I put her in day care so I could work. The day care would not perform the catheterization because of legal concerns. I was scared that if I did not work that I would be sanctioned and our family would go without needed food or some other necessity. So I worked and my daughter did not get catheterized that day. Her health was put at risk so I could meet unreasonable obligations in order to get my TANF check to take care of my family"
Statement of a Maine mother from collection of Maine Equal Justice Partners.

Research shows significant numbers of children with disabilities live in poverty and many are in TANF families. The number of poor children with disabilities has increased dramatically over

Economic Security: Low Job Skills and Mental Health Problems are Key Barriers, Research Forum on Children, Families and the New Federalism, August 2001, <http://www.researchforum.org>, summarizing the findings of Danziger, et al.; Surjeet K. Ahluwalia, Sharon M. McGroder, Martha Zaslow, Elizabeth Hair, *Symptoms of Depression Among Welfare Recipients: A Concern for Two Generations*, Child Trends, December 2001, a discussion of the problems facing both adults and children with mental impairments in TANF, see Elisa Rosman, Jan McCarthy, and Maria Woolverton, *Focusing on Families in Welfare Reform Reauthorization: Adults with Mental Health Needs and Children with Special Needs*, National Technical Assistance Center for Children's Mental Health, Georgetown University Child Development Center, October 2001. This series of nine short issue briefs is available at <http://gucdc.georgetown.edu>.

¹⁰ Martin Gerry, Candace Shively, *The Kansas Learning Disabilities Initiative*, National Technical Assistance Center for Welfare Reform, University of Kansas, and Kansas Department of Social and Rehabilitative Services, January 1999; *Learning Disabilities: A Report by the State of Washington Department of Social and Health Services, Economic Services Administration, Work First Division*, September 1998; Barusch, Taylor, et al., *Understanding Families with Multiple Barriers to Self Sufficiency: Final Report*.

¹¹ Barusch, Taylor, et al., at 44-45, Table 14. "When asked if their health interfered with specific activities, 38.4 percent answered that their health interfered a lot with vigorous activities, 12.0 percent reported that their health interfered a lot with moderate activities, 27.5 percent reported a lot of difficulty climbing several flights of stairs, and 26.9 percent reported a lot of difficulty walking more than one mile."

the past two decades — from 3.94 million in 1983 to 4.99 million in 1996.¹² Using data from the National Survey of America's Families, Child Trends reports that children in families receiving welfare are more likely to have a physical, learning or mental health condition that limits their activity (20 percent of the children) than children whose families have left welfare (14 percent of the children). Additionally, children of current and former recipients are more likely than other poor children to have such conditions.¹³ In July 2002, the General Accounting Office reported that 15 percent of TANF families include a child with an impairment.¹⁴ The MDRC study found that one-fourth of non-employed mothers receiving TANF had a child with an illness or disability that limited the mothers' ability to work or attend school.¹⁵ The Michigan study of TANF recipients in one urban county found that 22 percent of respondents had a child with a health, learning or emotional problem.¹⁶ In a study of California families receiving welfare, a 1996 study found that "the presence of chronically ill and disabled children has a significant negative impact on mothers' labor force participation, even after controlling for differences in women's human capital characteristics, household configuration, and other income." The presence of a child with a disability or chronic health problem was associated with a 36 to 90 percent reduction in the odds that the mother worked, depending on the number of children with disabilities in the family.¹⁷

Families with a member with a disability - multiple barriers.

Case #4

"I suffer from anxiety, panic and social phobia disorder. I have four children and the youngest two need to use a respiratory machine every four to eight hours. This makes child care very hard to find and also very expensive. In the past, I tried to attend a Job Club ... but I was too sick and overwhelmed to go and I couldn't do it. ... About six months ago, I got a doctor's note that said that I couldn't work at that time due to my problems. My caseworker told me that "the state is not going to go for this," and that I would have to work." Statement of a Maine mother from collection of Maine Equal Justice Partners.

Case #5

"My name is Sandra. I am a 27 year old mother of three boys ages 12, 8 and 1. My children and I live with my mother, two of my mother's grandchildren, and my adult brother, Billy, who is severely mentally retarded. I went to live with my mother when I left an abusive situation a year and a half ago. I have had many problems that keep me from working full-time, especially taking care of my disabled family members. Two of my children have medical problems that I must deal

¹² Glenn T. Fujiura, Kiyoshi Yamaki, *Trends in Demography of Childhood Poverty and Disability*, published in *Exceptional Children*, Vol. 66, No.2, 187, 190-192, Winter 2000. This study looked at annual data sets – 1983 through 1994 – from the National Health Interview Survey, for children ages three to 21.

¹³ Kathryn Tout, Juliet Scarpa, Martha J. Zaslow, *Children of Current and Former Welfare Recipients: Similarly at Risk*, Child Trends, March 2002, <http://www.childtrends.org/PDF/leaversRB302.pdf>.

¹⁴ U.S. General Accounting Office, *Welfare Reform: Outcomes for TANF Recipients with Impairments*, GAO-02-884, July 2002, available at <http://www.gao.gov>.

¹⁵ Polit, London, and Martinez, May 2001.

¹⁶ Sandra Danziger, et al., February 2000.

¹⁷ Meyers, Lukemeyer, Smeeding, *Work, Welfare, and the Burden of Disability: Caring for Special Needs of Children in Poor Families*, Center for Policy Research, Syracuse University, April 1996, <http://www-cpr.maxwell.syr.edu/incomsec/incomlst.htm>.

*with. Shawn, my eight year old, has Attention Deficit and Hyperactivity Disorder. I must make sure that he takes his medication. I take him to therapy each week. Mark, my baby, was hospitalized for several weeks when he was born with a severe respiratory infection and seizures. He is still sickly and has many doctors appointments. My brother cannot take care of himself. My mother is in poor health herself, suffering from high blood pressure, anxiety and other health problems. She needs my help to take care of Billy. I cook food for him, help feed him, change his clothes, and help him with bathing and other personal care. My mother is often too tired and sick to do these things and Billy cannot do them for himself. ... I have worked for most of my adult life at various jobs ... I have had learning disabilities throughout my life, which have made it hard to keep a job. Also, I miss so much work to take care of my family that I get into trouble for attendance. I have participated in job training programs offered by the Welfare Department, which have been useful for me. But I could not go to school regularly because of my family responsibilities. I wish I could work steady and support my family. But these problems often cause me to miss work, and I don't see that changing in the future."*¹⁸

It is common for families with a parent with a disability or a child with a disability to have other barriers as well.¹⁹ These barriers include having more than one health condition, more than one person with disabilities in the family, and the range of barriers faced by other low-income parents as they attempt to work, such as lack of child care, inadequate or non-existent transportation, and limited education and skills. In its July 2002 report, the General Accounting Office found that eight percent of TANF families include both a parent with impairments and a child with impairments.²⁰

A study prepared by the University of Kentucky Institute on Women and Substance Abuse for the Kentucky Cabinet for Families and Children found that the majority of TANF clients have at least one significant barrier to becoming self-sufficient.²¹ Two-thirds (67 percent) of the Targeted Assessment Project clients had significant mental health problems alone or in combination with domestic violence, substance abuse, and/or learning problems. Mental health problems were a factor in all cases assessed with three problems. Of those assessed with only one issue, most had a serious mental health problem, such as major depression, agoraphobia, bipolar disorder, anxiety disorder, post-traumatic stress disorder, or psychotic disorders. Of those assessed with a mental health problem, 73 percent said that they were not receiving services to address the problem, and 44 percent said they had never received services.

As the number of barriers a parent faces increases, the chances that the parent will be working decrease. It also is very likely that the existence of some impairments, such as clinical depression, low intelligence, and learning disabilities, exacerbate a parent's inability to address

¹⁸ Sharon Dietrich, Community Legal Services, Philadelphia, PA, *Many Welfare Recipients Could Not Meet TANF Proposals for 40 Hours of Work*, page 15.

¹⁹ For a more detailed discussion, see Heidi Goldberg, *Improving TANF Outcomes for Families with Barriers to Employment*, page 7; and Eileen Sweeney, *Recent Studies Indicate that Many Parents Who are Current or Former Welfare Recipients Have Disabilities or Other Medical Conditions*, pages 18-21.

²⁰ U.S. General Accounting Office, cited above.

²¹ *The Targeted Assessment Project and TANF Reauthorization: Preliminary Client Data, July 1, 2000 – December 31, 2001*, prepared by University of Kentucky Institute on Women and Substance Abuse and Center on Drug and Alcohol Research for the Kentucky Cabinet for Families and Children, May 23, 2002

other barriers and to comply with program rules. In its *Temporary Assistance for Needy Families (TANF) Program: Second Annual Report to Congress*, the Department of Health and Human Services stated that, “[a]lthough there have been dramatic gains in work for many TANF families, too many families with multiple barriers to success are at risk of being left behind.”²² The Urban Institute has found that “[p]erhaps the strongest predictor of not participating in work activity is the presence of multiple obstacles.”²³ A Michigan study similarly found that the more barriers a woman has, the less likely it is that she is working. The authors predicted that women with four to six barriers had only a 41.4 percent probability of working at least 20 hours per week and women with seven or more barriers had only a 5.6 percent probability of working at least 20 hours per week.²⁴ As a result, it is important not only to have identified the barriers a parent or family faces but then to work to reduce the number of barriers to increase the likelihood that the parent can both secure and retain employment.

Consequences for Families with Disabilities in TANF

Some of the studies also have looked at the outcomes for TANF families in which there is a member with a disability. They found the following:

Families are often inappropriately sanctioned.

Case #6

*“I brought my son to Children’s Hospital and Dr. Rudd discovered my son has CP [cerebral palsy]. While my son was in the hospital, I got sanctioned because I wasn’t going to school for the mandatory 20 hours a week. They told me to get a doctor’s note and I did, but they haven’t taken my sanctions off. They need to have a different program for parents whose children are disabled.”*²⁵ Minnesota parent

Case #7

“I suffer from multiple mental illnesses. I have two children who live at home with me, my son, who is 17, and my daughter who is 10. I am getting treatment and eventually hope to get to the point where I can work, but my doctor believes it will take a while. In the summer 1998, ASPIRE verified that I could not work because of my disabilities. In October, 1998, even though nothing had changed, ASPIRE had me sign a family contract that required me to work 25 hours per week through “Build, Develop and Learn” (BDL). I signed it because I thought I had to and I was told that my family would be sanctioned if I didn’t sign it. Apparently the goal of this contract was to move me into a “full time job”. In the spring of 1999, I was sanctioned for not going to a meeting with my BDL worker. I appealed and had a hearing over the phone. My counselor wrote a letter ... she explained how my disabilities affect me, ... and that I needed more help with my disabilities before I could think about getting a job. The doctor said that making me participate would be counter-productive to my treatment. I’m not sure how, but we lost the hearing. Luckily,

²² *Temporary Assistance for Needy Families (TANF) Program: Second Annual Report to Congress*, U.S. Department of Health and Human Services, August 1999, at 140.

²³ Pamela J. Loprest, Sheila R. Zedlewski, *Current and Former Welfare Recipients: How Do They Differ?* Urban Institute, Discussion Paper 99-17, November 1999, <http://www.urban.org/>

²⁴ Danziger, Corcoran, et al., at 23.

²⁵ *Faces of Change*, Alliance for Children and Families, <http://www.alliance1.org/Home/Home.asp>.

I found help at Maine Equal Justice Partners. We appealed ... and DHS's attorney agreed with us that I could not work and DHS dropped the sanction. ... I hope no one with mental illness has to go through what I did." Statement of Maine mother, collection of Maine Equal Justice Partners.

Most states impose severe sanctions on families receiving welfare when a parent fails to comply with TANF work requirements. More than two-thirds of the states impose full-family sanctions, stopping aid to children as well as parents when a parent fails to meet a program requirement. Nearly half of these states impose the full-family sanction the first time a parent fails to meet the requirement. Various research studies have analyzed the extent to which parents who have been sanctioned were unable to understand what was required of them to comply with state rules and did not understand the consequences for failing to comply — in other words, rather than willfully ignoring program rules, the parent's barriers impeded her ability to comply with the rules.²⁶ This may have happened because the requirements or activities were inappropriate for the parent, the parent never understood the program rules, the parent failed to receive the information in essential accessible format and other alternative means of communication, or the parent did not receive other support she needed to be able to comply. In many cases, the states do not identify the barriers or develop appropriate activities and services for people with barriers. Then, when the family fails to meet program requirements, a sanction is imposed.

Studies suggest that high numbers of families with a member with a disability are being sanctioned. For example:

- MDRC found that, “[w]elfare recipients with multiple health problems and with certain health problems (notably, physical abuse, risk of depression, having a chronically ill or disabled child) were more likely than other recipients to have been sanctioned in the prior year.” And, among those who had left welfare, “[w]elfare leavers with multiple health problems were more likely than other women who had left welfare to say that they had been terminated by the welfare agency rather than that they left of their own accord.”²⁷
- Studies in Utah and Delaware suggest that parents who have learning disabilities or who have low intelligence find it difficult to understand and comply with the program's rules.²⁸
- One-third of the families who were sanctioned in Utah, thereby losing their family's entire cash benefit, cited an individual health condition as the reason for their failure to participate; one-fifth cited mental problems.²⁹

²⁶ See, for example, studies in Delaware and Iowa: David J. Fein, Wang S. Lee, *Carrying and Using the Stick: Financial Sanctions in Delaware: a Better Chance Program*, Abt Associates, Inc., May 1999, <http://www.abtassoc.com/reports/ES-Sanfin3.pdf>; and Lucia Nixon, Jacqueline Kauff, Jan L. Losby, *Second Assignments to Iowa's Limited Benefit Plan*, Mathematica Policy Research, August 1999, at 19, 23, <http://www.mathematica-mpr.com/PDFs/secondlbp.pdf>.

²⁷ Polit, London and Martinez, 2001.

²⁸ Barusch, Taylor, et al., at 51; Fein, Lee, at 13, 22.

²⁹ Michelle K. Derr, *The Impact of Grant Sanctioning on Utah's Families*, University of Utah, October 1998.

- In Iowa, one-fifth of parents who were placed in the state's limited benefit plan a second time – the plan in which families that have not complied with program rules receive a reduced benefit (akin to a sanction) – said that their disability/health contributed to their being returned to the sanction status, while almost three out of ten cited their lack of understanding of program rules.³⁰

Families who leave TANF due to sanctions are less likely than others who leave TANF to be working, and if they are working, they are likely to be earning less than others who have left TANF.³¹ A recent study in three cities — Boston, Chicago, and San Antonio — also found that children in sanctioned families are more likely to have behavior problems and emotional problems than children in other families on welfare or who never received welfare.³²

A medical study issued in 2002 provides additional information about young children in sanctioned families. The study looked at the impact of sanctions on the health of infants and toddlers. It was conducted in six cities from August 1998 through December 2000: Baltimore, Boston, Little Rock, Los Angeles, Minneapolis, and Washington, DC. The researchers found that households with children aged 36 months or younger whose welfare benefits had been terminated or reduced by sanctions had odds of being food insecure 1.5 times as great as comparable households whose benefits were not decreased. In addition, young children in families whose welfare benefits had been terminated or reduced by sanctions had 1.3 times the odds of having been hospitalized since birth.³³

Families with a family member with disabilities often are not working after leaving TANF.

Case #8

“My name is Eve. I live in Philadelphia. I have received welfare since about 1997. I have three children, my son Woodley, who is now grown up and away in Job Corps; my 28-year-old son, Naquaine; and my son, Andrew, who died as an infant. I am the sole caregiver for Naquaine,

³⁰ Nixon, Kauff, and Losby, August 1999, cited in [footnote 26](#). Chronic health conditions identified as contributing to being placed in the program included drug addiction, manic depression, and chronic asthma.

³¹ Heidi Goldberg, *A Compliance-Oriented Approach to Sanctions in State and County TANF Programs*, Center on Budget and Policy Priorities, March 2001, <http://www.cbpp.org/3-28-01tanf.pdf>.

³² P. Lindsay Chase-Lansdale, Rebekah Levine Coley, Brenda J. Lohman, Laura D. Pittman, *Welfare Reform: What About the Children? Welfare, Children and Families: A Three-City Study*, Policy Brief 02-1, Johns Hopkins University, 2002, http://www.jhu.edu/~welfare/19382_Welfare_jan02.pdf. “We need to attend much more carefully to the plight of families experiencing welfare sanctions. Sanctioned families have a number of characteristics that serve as markers of concern for the healthy development of children and youth. As such, state and federal governments should explore options for identifying and reaching out to the most disadvantaged and high-risk families involved in the welfare system. Possible policy options include assistance to bring families into compliance with rules before they are sanctioned, closer monitoring of sanctioned families, and the provision of additional supports, such as mental health services, academic enrichment, after-school programs, and other family support services.” *Id.*

³³ Children's Sentinel Nutrition Assessment Program, *The Impact of Welfare Sanctions on the Health of Infants and Toddlers*, July 2002, *Arch Pediatr Adolesc Med*, Vol. 156, 678-683, <http://dccc2.bumc.bu.edu/csnappublic/welfaresanctions.htm>. In the article, the authors conclude that, “Child health professionals should be concerned that increasingly stringent requirements proposed for the 2002 welfare reform law reauthorization may further jeopardize the health of some of America's most vulnerable children as the economic cycle, sanctions, and time limits simultaneously decrease families' resources.”

*who suffers from autism. Naquaine needs 24 hour a day care. I have been the only one to provide it since my husband left a long time ago. Because I need to take care of Naquaine, I simply cannot work 40 hours a week, every week. ... Things are always coming up with Naquaine that make me drop everything to take care of him. If his bus is late, I need to wait with him. If he acts up in school, the teachers call me and expect me to come immediately. The after-school program has been a great help. But the welfare office cut off my childcare subsidy, and the program is getting ready to put him out, because I cannot pay. I am so worried about losing my care for him. When you are a single parent, it is very hard to both work and take care of your children. When I came on welfare, I tried to do it by working the 11:00 pm to 7:00 am shift, when my children were sleeping, so I could take care of them during the day. I left Naquaine and my baby Andrew with my older son when I went to work, because I didn't have anyone else to care for them. My baby died one night while I was at work; he just stopped breathing. They say it was Sudden Infant Death. I feel like if I had been there Andrew would not have died. People on welfare have no problem working if their children are safe. I want to work. I've worked all my life. But it always ends up that I get fired because of missing work. Everything may be going well on the job, then something comes up, and I lose it."*³⁴

Many parents with disabilities who have left TANF do not work; some have lost jobs they held when they left TANF.

For example:

- In a Colorado study, 35 percent of the former TANF recipients surveyed were not working at the time of the survey. Almost one-third said that personal health problems or other personal problems prevented them from working.³⁵ That study concluded: "We need to attend much more carefully to the plight of families experiencing welfare sanctions. Sanctioned families have a number of characteristics that serve as markers of concern for the healthy development of children and youth. As such, state and federal governments should explore options for identifying and reaching out to the most disadvantaged and high-risk families involved in the welfare system. Possible policy options include assistance to bring families into compliance with rules before they are sanctioned, closer monitoring of sanctioned families, and the provision of additional supports, such as mental health services, academic enrichment, after-school programs, and other family support services."
- In a Mississippi survey of people who left TANF early in 1998, three to eight months later 53 percent had not worked since leaving TANF and 65 percent were not working at the time of the survey. Of the latter group, 27 percent reported they were physically or mentally ill.³⁶ In the article about this study, the authors conclude that, "Child health

³⁴ Sharon Dietrich, Community Legal Services, Philadelphia, PA, *Many Welfare Recipients Could Not Meet TANF Proposals for 40 Hours of Work*.

³⁵ *Evaluation of the Colorado Works Program: First Annual Report*, Berkeley Planning Associates, November 1999, at 29, Figure 2-4.

³⁶ Jesse D. Beeler, Bill M. Brister, Sharon Chambry, et al., *Tracking of TANF Clients, First Report of a Longitudinal Study: Mississippi's Temporary Assistance for Needy Families Program*, Center for Applied Research, Millsaps College, revised January 1999, at 12, Table 8.

professionals should be concerned that increasingly stringent requirements proposed for the 2002 welfare reform law reauthorization may further jeopardize the health of some of America's most vulnerable children as the economic cycle, sanctions, and time limits simultaneously decrease families' resources."

- A study by the Hudson Institute and Mathematica Policy Research of Milwaukee families who were involved in the conversion of the Wisconsin welfare plan from AFDC to Wisconsin Works (W-2), found that among those who reported a personal disability or health problem or the disability or health problem of a family member, 23 percent were not employed, were not in a W-2 work training placement and did not receive either SSI or a kinship care payment.³⁷

Anecdotal evidence suggests that, to avoid the ultimate loss of benefits, some TANF recipients with disabilities were shifted off TANF and onto the SSI roles before they could take advantage of the TANF supports and services that might have led to employment.

Parents with a child with disabilities face more barriers to work.

Case #9

*"My name is Theresa. I am a 33 year old ...mother of three children ages 13, 10 and 8. I currently receive TANF for myself and my three children, and I am likely to reach my five-year lifetime limit for TANF in March, 2003. My 10-year-old Chae suffers from Attention Deficit Hyperactivity Disorder and major depression. His needs prevent me from working in a full-time job. I participated in several job training programs offered by my welfare caseworker ... I did not have a good experience at these programs, but I really wanted to find a way to get the education and training that I needed to find a job that would support my family. In June, 2000, I decided to close my TANF case and join the Army. I thought the Army would provide me with training and job advancement that I did not get through the welfare department. While I was in the Army my children were cared for by my relatives. But several months after I enlisted, Chae was diagnosed with ADHD and major depression. He was even hospitalized for some time due to his depression. Because of his illness and hospitalization, I was forced to get a leave of absence and later an Honorable Discharge from the Army in order to take care of him. I returned to Philadelphia and re-opened my TANF case. I currently meet my work requirements ... by doing 20 hours per week of community service, as well as an independent job search. I am afraid of working too much. Because of what happened when I was in the Army and not around for Chae. I am very scared that he can be hospitalized again if I don't spend enough time taking care of him. I very much want to find a job that will enable me to get off welfare and support my family. But I am also very concerned about my children's health and well being. I feel that I am in a "lose-lose" situation."*³⁸

³⁷ Rebecca Swartz, Jacqueline Kauff, Lucia Nixon, Tom Fraker, Jay Hein, Susan Mitchell, *W-2: Converting to Wisconsin Works: Where Did Families Go When AFDC Ended in Milwaukee?* Hudson Institute and Mathematica Policy Research, 1999, at 37-38, Table 6-4, <http://www.mathematica-mpr.com/PDFs/w2report.pdf>.

³⁸ Sharon Dietrich, Community Legal Services, Philadelphia, PA, *Many Welfare Recipients Could Not Meet TANF Proposals for 40 Hours of Work*, p.21.

In addition, research indicates that parents with children with disabilities are less likely to leave TANF, and when they do leave welfare for work, they are less likely to have the flexibility on their jobs to meet their children's needs. For example:

- The presence of a child with disabilities in a family has been found to dramatically reduce the chances that the parent will be working. A 1996 Syracuse University study of California families receiving welfare found that “the presence of chronically ill and disabled children has a significant negative impact on mothers’ labor force participation, even after controlling for differences in women’s human capital characteristics, household configuration, and other income.” The presence of a child with a disability or chronic health problem was associated with a 36 to 90 percent reduction in the odds that the mother worked, depending on the number of children with disabilities in the family.³⁹
- In a study of women in urban and rural Michigan who receive TANF cash assistance and who have children with disabilities, families identified three systemic barriers to self-sufficiency for their families: poorly trained welfare caseworkers who do not understand the complexities of raising a child with disabilities, limited public transportation (nonexistent in rural areas and unreliable, inaccessible, or limited in range in urban areas) and inadequate child care.⁴⁰

State Responses to the Research

The results of these studies suggest that states need to design their programs better to identify and assist parents with disabilities and parents of children with disabilities. Two key features of the 1996 law make these improvements possible: the flexibility states have to design their programs to assist families to move to self sufficiency and the availability of federal TANF funds. The decline in cash assistance caseloads — freeing up TANF funds to provide work supports and to assist families with barriers — provided some states with the opportunity to look more closely at how best to meet the needs of this population.⁴¹

Some states have been moving in this direction. Some of the steps states have taken include:

- *Reducing inappropriate sanctions.* Tennessee has established a sanction review procedure that determines whether the state followed its policies and also provides the family with a second chance to come into compliance. In 2001, Maine adopted a pre-sanction review procedure as well. Vermont, Iowa, and Utah have procedures that help to

³⁹ Marcia K. Meyers, Anna Lukemeyer, Timothy Smeeding, *Work, Welfare, and the Burden of Disability, Caring for Special needs of Children in Poor Families*, Center for Policy Research, Syracuse University, April 1996, <http://aspe.hhs.gov/daltcp/reports/wrkwlfs.htm>.

⁴⁰ Barbara W. LeRoy, Donna M. Johnson, Sharonlyn Harrison, *Open Road or Blind Alley? Welfare Reform, Mothers and Children with Disabilities*, Skillman Center for Children, Wayne State University, Occasional Paper Series 2000, No. 4, November 2000, <http://www.skillmancenter.culma.wayne.edu>

⁴¹ For information on TANF spending, see U.S. Department of Health and Human Services, *Temporary Assistance for Needy Families (TANF) Fifth Annual Report to Congress*, February 2003, Tables 2:8 through 2:15, <http://www.acf.hhs.gov/programs/ofa/indexar.htm>, and Zoe Neuberger, *TANF Spending in Federal Fiscal Year 2001*, Center on Budget and Policy Priorities, March 2002, <http://www.cbpp.org/3-21-02tanf.htm>.

better identify families with disabilities who need greater supports or modifications of rules in order to come into compliance with program rules.

- *Tailoring services to the individual needs of families with a member with disabilities so that the parent can move towards employment.*⁴² Tennessee has established the “Family Services Counseling” (FSC) program designed to help parents address barriers. The 100-plus masters-level social workers across the state who staff the FSC program have the authority to modify program rules so that a family can comply; secure treatment, education and training; and otherwise take steps to help parents and children with barriers such as mental health, learning disabilities, domestic violence and substance abuse. Pennsylvania has created the “Maximizing Participation Project” (MPP) for people with barriers who cannot meet the current work requirement and are approaching their five year time limit. MPP provides comprehensive assessments and intensive case management to help parents address barriers. There is no minimum work requirement in MPP. Currently, 1700 parents with disabilities voluntarily participate in MPP.⁴³ Vermont has designed a collaborative effort between its TANF agency and the vocational rehabilitation agency, creating 11 new counselor positions in the VR agency, to work with TANF families with disabilities.⁴⁴ Kentucky’s 32 Targeted Assessment Specialists, employed by the University of Kentucky under a contract with the state’s TANF agency, are on-site at public assistance and child protective services offices in 18 communities to conduct assessments, pre-treatment, and follow-up services focused on mental health, domestic violence, substance abuse and learning problems.⁴⁵
- *Adjusting requirements when a parent’s full attention needs to be devoted to the health and welfare of a child with a disability.* Illinois recently modified its rules to provide for a “family care” barrier, stopping the TANF time clock for a parent who provides full-time care required by a child under age 18 or a spouse due to their medical condition. California has a rule similar to the Illinois rule, providing that if a person’s care-taking responsibilities for a child or other family member who is ill or incapacitated significantly impairs the ability of the person to be regularly employed or to participate in welfare-to-work activities, the person will be exempt from the work rules and the months will not count toward the person’s time clock.

Helpful guides for state and county administrators on how to identify and serve families with a member with a disability have been published, often with funding from HHS.⁴⁶ In addition, in

⁴² For greater detail about these and other state programs, see Heidi Goldberg, *Recent TANF Proposals Would Hinder Successful State Efforts to Help Families Overcome Barriers to Employment and Find Better Paying Jobs*, Center on Budget and Policy Priorities, April 2002, <http://www.cbpp.org/5-9-02tanf.pdf>.

⁴³ Jonathan M. Stein, Brendan Lynch, *The Administration’s Proposed Increases in TANF Work Requirements are Unfair to Pennsylvania TANF Recipients with Disabilities*, Community Legal Services, April 2002.

⁴⁴ Johnette T. Hartnett, *Vermont’s Response to Welfare Reform for People with Disabilities: An Evaluation of Vermont’s Vocational Rehabilitation (VR) and PATH Partnership*, University of Vermont, Fall 2002.

⁴⁵ See study referred to in footnote 22.

⁴⁶ See Gretchen Kirby, Jacquelyn Anderson, *Addressing Substance Abuse Problems Among TANF Recipients: A Guide for Program Administrators*, Mathematica Policy Research, July 2000, <http://www.mathematica-mpr.com/PDFs/addresssubstance.pdf>; Michelle Derr, Heather Hill, LaDonna Pavetti, *Addressing Mental Health Problems Among TANF Recipients: A Guide for Program Administrators*, Mathematica Policy Research, July 2000,

2001, the Office for Civil Rights at HHS issued guidance to states and counties on the applicability of Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act in TANF-funded programs.⁴⁷ This technical assistance has helped state administrators to focus on ways to assist parents with disabilities as well as parents with a child with a disability.

The HHS Inspector General's report provides some information about the types of actions states are taking to identify families with barriers to work and then concludes that "states are still facing challenges": "States report facing several challenges in addressing recipients with barriers to employment. At least 13 states report they do not have the capacity to serve all recipients with some of the barriers we addressed. Forty-one states do not have any specific strategies to help recipients who face multiple barriers. Only nine states report using pilot programs to implement new approaches for any of these populations. Additionally, few states have information about the barriers faced by recipients who have been sanctioned or have strong evidence about the effectiveness of their strategies to help recipients with the barriers we addressed in this inspection."⁴⁸

Solid TANF methods of administration can make all the difference for people with disabilities as they struggle to support and nurture their families and live independently. However, experience to date suggests that while TANF's potential is being realized for some families with a disability, the state's TANF rules can also unravel a family if the parent's disability is not identified and services and supports are not provided. The following examples from Colorado set out starkly the differing consequences. These examples are taken from a report by the Governor of Colorado's Task Force on TANF implementation that focused on several barriers, including mental health issues, chronic health problems, physical disabilities, learning disabilities, language barriers, and multiple barriers.⁴⁹ The examples were included in testimony before the House Human Resources Subcommittee of the Ways and Means Committee on April 11, 2002.⁵⁰

<http://www.mathematica-mpr.com/PDFs/addressmental.pdf>. See also, Rebecca Brown, Evelyn Ganzglass, *Serving Welfare Recipients with Learning Disabilities in a Work First Environment*, National Governors Association Center for Best Practices, 1999, <http://www.nga.org>; Amy Brown, *Beyond Work First: How to Help Hard-to-Employ Individuals Get Jobs and Succeed in the Workforce*, Manpower Demonstration Research Corporation, 2001, <http://www.mdrc.org/Reports2001/HardtoServe/MDRCHow-ToHardtoEmploy.pdf>; M. Robin Dion, Michelle K. Derr, Jacquelyn Anderson, LaDonna Pavetti, *Reaching All Job Seekers: Employment Programs for Hard-to-Employ Populations*, Mathematica Policy Research, October 1999, <http://www.mathematica-mpr.com/PDFs/hdemploy.pdf>.

⁴⁷ Office for Civil Rights, U.S. Department of Health and Human Services, *Prohibition Against Discrimination on the Basis of Disability in the Administration of TANF (Temporary Assistance for Needy Families)*, January 2001, <http://www.hhs.gov/ocr/prohibition.html>; see also Eileen P. Sweeney, *HHS Guidance Explains How Federal Laws Barring Discrimination Against People with Disabilities Apply in State and County TANF Programs*, Center on Budget and Policy Priorities, February 2001, <http://www.cbpp.org/2-26-01wel.htm>. In his reply to the HHS Inspector General's report, cited at footnotes 5 and 45, at page 23, HHS Assistant Secretary for Children and Families Wade Horn indicated that there has been broad dissemination of the OCR guidance on TANF and disabilities.

⁴⁸ HHS Office of the Inspector General, cited at footnote 5, above, page iii. The report focused on eight barriers: substance abuse, domestic violence, mental health issues, chronic health problems, physical disabilities, learning disabilities, language barriers, and multiple barriers.

⁴⁹ Both clients' stories are printed in *Moving Forward with Welfare Reform*, The Governor's Task Force on Welfare Reform Report, Colorado, September 12, 2000.

⁵⁰ Paul Marchand, Co-chair of Consortium for Citizens with Disabilities TANF Task Force, testimony before

Case #10

“Client A was tested and had an IQ of 67. She was sent to Vocational Rehab and then instructed to seek work. She received childcare for two occasions and then was sanctioned in Colorado Works. Her family became homeless in November 1998 and the children were placed in foster care in December 1998.”

Case #11

“Client B has an IQ of 67 and is a victim of domestic violence. There is suspicion of brain damage as a result of abuse. She cannot communicate well, she is conscientious but has few skills. She has an anxiety disorder which cannot be treated because of her heart problem. She sees a physician weekly to manage blood thinning medications. She had surgery for a valve replacement one year ago. She was assigned to a community college program which reported that she would be doing fine but then the next day she couldn’t remember what she had learned. It takes the parent approximately one month to learn a bus route. The county required that she find a job in six months. Later that expectation was lowered to ten hours of time within her supported living program.”

“The description of the steps the state took to help Client B provides a sense of the types of steps that states will need to take in order to help some parents with disabilities to maximize their potential. Unfortunately, no steps — not even ongoing child care for her children — were taken to assist Client A, with the tragic consequence that she was sanctioned, lost her home, and then lost custody of her children.”

Proposals to Improve Outcomes for Families with Disabilities in TANF

It is clear that disability is a significant issue within the TANF program and that the unique needs of individuals with disabilities must be addressed if the system is to achieve the goal of securing employment and economic independence for TANF recipients who live with a disability. A number of improvements needed in the TANF law have been proposed by organizations representing people with disabilities to assist states to best meet the needs of families with disabilities.⁵¹ The National Council on Disability makes the following recommendations to strengthen the ability of the states to support families with disabilities in their welfare system.

1. Increased TANF and Child Care Funding. Last year, the Congressional Budget Office estimated that the costs to states of meeting new work requirements and increased participation

Human Resources Subcommittee, Ways and Means Committee, April 11, 2002.

http://www.aucd.org/legislative_affairs/testimony_tanf.htm. In the testimony, Mr. Marchand stated: “It should not be acceptable to the Congress that even one parent with disabilities or one parent caring for a child with disabilities faces these types of consequences in TANF. Unfortunately, the research suggests that problems like this are all too frequently occurring across the country, at great personal expense to parents and children.”

⁵¹ For a more detailed discussion, see two documents prepared by the TANF Task Force of the Consortium for Citizens with Disabilities, *Principles Guiding the Reauthorization of TANF*, and *TANF Reauthorization Policy Priorities*, both of which are included in the testimony of Paul Marchand, The Arc, on behalf of the Consortium before the Human Resources Subcommittee of the Ways and Means Committee, April 11, 2002. The *Policy Priorities* also are available on the CCD website, <http://www.c-c-d.org/tanfreautho.htm>.

rate targets would be up to \$11 billion over five years (roughly \$6 billion in work program costs and \$5 billion in increased child care costs for work program participants). The Center for Law and Social Policy estimates that the five-year costs of implementing proposed increased work and participation rate requirements are in the range of \$15.1 billion above what states would otherwise spend under current law.⁵² Without the funding needed to meet the new requirements, states will have to cut effective programs now funded with TANF in order to comply. In other words, there already is significant evidence that states need more than they currently receive annually in order to simply maintain the programs they currently have in place.

The Congressional Budget Office estimated that :an additional \$4.55 billion in child care funding over the next five years is needed to ensure that the mandatory federal child care funding stream, state funds used to match these federal funds, and the TANF funds devoted to child care keep pace with inflation. CBO's \$4.55 billion figure may understate the cost of maintaining current services because the estimate assumes that states will be able to maintain their current levels of using TANF for childcare. This is unlikely to occur. In 2002, states spent \$1.6 billion *more* than their annual TANF allotments, by drawing on unspent TANF funds carried over from prior years.⁵³ These "carry-over" funds have been exhausted or nearly exhausted in most states. To bring spending in line with their annual TANF block grant allotment, many states will have to *cut* TANF funding for various programs, including child care programs, in the next few years. The funding shortage will hit hardest families who have children with disabilities who may require more expensive specialized care.⁵⁴

Not surprisingly, the types of services and supports that families with a member with a disability need in order to succeed are often intensive, individualized, long-term, and more costly than the services that families without barriers need. If no additional funds are added to the basic TANF block grant, as inflation further erodes the value of the TANF block grant, it will become increasingly difficult for states to pay for the services and supports that people with disabilities need in order to be able to move successfully from welfare to work. Additional funding for both the TANF block grant and the child care program will be necessary to enable these programs to meet federal requirements and programmatic needs for families with disabilities.

2. Screening and Assessment. The reauthorization must include provisions to ensure that parents with barriers, including disabilities and other health conditions, are screened in a timely manner with appropriate diagnostic tools to determine if a more comprehensive assessment is needed. Comprehensive assessments must be provided by qualified professionals to identify barriers to employment and to suggest to state or county staff the steps needed to assist the family. As part

⁵² Steve Savner, Julie Strawn, Mark Greenberg, *TANF Reauthorization: Opportunities to Reduce Poverty by Improving Employment Outcomes*, April 2002, <http://www.clasp.org>.

⁵³ Zoe Neuberger, *Annual TANF Expenditures Remain \$2 Billion Above Block Grant*, Center on Budget Policy and Priority, October 30, 2002

⁵⁴ CBO's \$4.55 billion figure may understate the cost of maintaining current services because the estimate assumes that states will be able to maintain their current levels of using TANF for childcare. This is unlikely to occur. In 2002, states spent \$1.6 billion *more* than their annual TANF allotments, by drawing on unspent TANF funds carried over from prior years. These "carry-over" funds have been exhausted or nearly exhausted in most states. To bring spending in line with their annual TANF block grant allotment, many states will have to *cut* TANF funding for various programs, including childcare programs, in the next few years.

of the screening and assessment process, states should also consider documentation from other systems of the existence of a disability in a family. The changes to TANF must also ensure that screening and assessments are voluntary on the part of TANF beneficiaries and that TANF beneficiaries with disabilities are not subjected to a sanction or closure for failing to participate in a screening or assessment. Screening and assessment results must be maintained in accordance with professional standards of confidentiality.

3. Sanctions. The federal legislation should prohibit a state from sanctioning a family until the state has: 1) taken steps to identify barriers, including disabilities; 2) provided the family with assistance in meeting the rules; and, 3) modified rules, if necessary to address the parent's or child's disability, so that the family can comply. The federal legislation should require states to have pre-sanction review procedures to reduce the chance of arbitrary and inappropriate sanctions being applied against a family with a family member with a disability. Based on the research on people with barriers and sanctions, it is reasonable to expect that greater numbers of parents with disabilities and other barriers will be sanctioned rather than helped under proposals for the new TANF program if they are not provided these protections.

4. State Flexibility. As pointed out in an earlier section of this paper, a key feature of the 1996 law that has made it possible for states to improve the way they support individuals with disabilities has been the flexibility states have to design their programs. The federal legislation should build on the 1996 statute by providing states with flexibility in how they define countable work activities, including rehabilitation and participation in other activities that will help the parent to become work-ready and how they determine the length of time that a particular individual or family will need the specific services or treatment. States must be given greater flexibility in how they will determine who will be exempt from the time limit and for how long.

TANF Families with disabilities must be provided with the services and supports needed to assist them to be able to successfully move into an independent work setting. States need the flexibility to design the individualized plans that parents with disabilities and children with disabilities need. For example,

- While 30 hours of activity each week is required by current law for families with children age six or older, states currently have the flexibility to require 40 hours of participation from families, but most have not chosen to do so universally. Instead of focusing on keeping participants busy for precisely 40 hours per week while they are on welfare, states have been able to place a greater emphasis on structuring work programs that provide the types of activities needed to move participants with and without disabilities into paid employment and off of welfare (regardless of the precise number of hours these activities add up to each week).
- Some parents with young children with disabilities are helped by the provision in the current statute that allows states to get full credit when a parent with a child under the age of six (regardless of disability) is working for 20 hours because they are able to meet their child's needs while being involved in a countable work activity part-time, for 20 hours. The flexibility states have to provide this modest protection must be retained.⁵⁵

⁵⁵ For a detailed discussion of why the 40 hour proposal is not feasible and will be impossible for many parents to

- Important information is available on the issue of state flexibility from the Vermont experience, which has created “hybrid” TANF/VR counselors in the VR agency. The agency’s experience with non-TANF closures may be instructive. Forty-eight percent of VR’s non-TANF successful closures to employment were people whose primary disability was mental illness, mental retardation, learning disability, or substance abuse. “The average length of time from applying for services to becoming employed for these individuals has been: mental illness, 15 months; mental retardation, 14 months; learning disability, 17 months; and substance abuse, 10 months.”⁵⁶ Without the flexibility to adapt work requirements and participation rates to the needs of the individuals, states would be forced to provide services to recipients which are less individualized and less appropriate to their needs, forcing recipients into a “one size fits all” approach that will be harmful to parents with disabilities and children with disabilities in TANF families.

The federal legislation should also allow states with waivers to continue under their waiver rules after reauthorization. A number of states were granted waivers to the welfare requirements under the old AFDC rules and were allowed to continue to operate under the same waiver, even when the rule differed from the new TANF rules. Often these rules allow states to provide more appropriate activities for parents than are permitted under standard federal TANF rules and, in some cases, to extend time limits for some parents with disabilities based on individual circumstances. It is important to note that NCD does not endorse a practice that exempts an individual from work requirements in lieu of providing the appropriate accommodations for the disability. However, extensions may be justified and especially important for families with care giving requirements that make it impossible for them to participate in required activities.⁵⁷

5. Training. The federal legislation should provide states with additional resources to train caseworkers and other staff who serve TANF recipients about issues unique to disabilities, including timely and effective screening, and the design of programs responsive to the needs of people with barriers of disability, identification and utilization of resources available in the community, and opportunities to develop collaborative relationships with other state and local public and private agencies, including grants to states and counties interested in supporting initiatives to achieve systemic improvements in addressing the needs of persons with diagnosed and undiagnosed disabilities. Caseworkers and other staff should also receive training in the unique needs of, and issues that have implications for, people with disabilities from diverse cultures. According to Fujiura, “If you have a disability in America, and you are from a diverse racial/ethnic group, odds are that you and your family live in poverty and that you will be poorer than others of your class and color.” <http://www.mswitzer.org/sem99/papers/fujiura.html>.

meet, see Sharon Dietrich, *Many Welfare Recipients Could Not Meet TANF Proposals for 40 Hours of Work*, Community Legal Services, April 2002, http://www.clsphila.org/Tanf_reauthorization.htm. The appendix to the paper provides examples of families in Pennsylvania who are working or trying to work and whose family circumstances would make it impossible to meet 40 hours as they cannot meet the current 30 hour requirement. In the majority of the examples, the parent is caring for children with disabilities or other family members with disabilities.

⁵⁶ Johnette T. Hartnett, cited above at footnote, page 7.

⁵⁷ Ruth Bourquin, *Persons with Disabilities and TANF: A Promising Massachusetts Model*, Massachusetts Law Reform Institute, March 2002.

6. Advisory Panels. The federal legislation should create advisory panels at the state level to assist the state in determining steps it should take to improve how it addresses the needs of people with barriers, including people with disabilities, in their TANF programs.

7. Health Care. The federal legislation should facilitate access to continued Medicaid or other health insurance coverage when recipients move from welfare to work. For any family, health coverage is essential. For a parent with a disability, continuing health care coverage when working may be the key support that allows the parent to work while addressing her medical needs. Transitional Medicaid Assistance (TMA) has helped to meet this need. For a parent with a disability, because TMA is time-limited, it will not fill the gap over time if the parent's job does not provide insurance — which is often the case for many low-wage jobs. However, it does help to ease the transition and, in states that have expanded Medicaid coverage to more parents at incomes higher than the very low TANF levels, the parent may be able to move into the expanded Medicaid coverage program after TMA. Because the Medicaid eligibility rules for children are more generous and the children can also enroll in the State Children's Health Insurance Program if they are over-income for Medicaid, TMA is most important for parents who typically have to meet more stringent income eligibility rules than children.⁵⁸ Studies in other income programs, such as SSI, have shown that fear of loss of health coverage is one reason that recipients with disabilities may be reluctant to work.⁵⁹ While there are no parallel studies in TANF, it would seem likely that similar concerns exist for parents with disabilities in TANF. The Transitional Medicaid Assistance program reauthorization period must parallel the reauthorization period for the rest of TANF.

8. Service Coordination. Because multiple services are available at the state and local level for adults and children with disabilities, the federal legislation should assist states to better coordinate and provide services needed by children with disabilities and their families, including coordination among state agencies to address the multiple challenges facing parents and their children with disabilities.⁶⁰

9. ADA and Section 504 Compliance. The federal legislation should be consistent with federal civil rights protections for individuals with disabilities under the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act, enabling states to easily comply with all three Acts. These recommendations would help states and counties meet their legal obligations to implement the long-standing national policy set forth in Section 504 of the Rehabilitation Act and the ADA to ensure that people with disabilities have equal and meaningful access to their TANF-funded programs, including the ability to benefit from state programs that assist families in transitioning from welfare to self-sufficiency.

⁵⁸ For information on state actions to expand Medicaid for parents, see Matthew Broaddus, Shannon Blaney, Annie Dude, Jocelyn Guyer, Leighton Ku, Jaia Peterson, *Expanding Family Coverage: States' Medicaid Eligibility Policies for Working Families in the Year 2000*, Center on Budget and Policy Priorities, February 2002, <http://www.cbpp.org/1-2-02health.pdf>.

⁵⁹ See, for example, *The Environment of Disability Policy Income: Programs, People, History and Context*, National Academy of Social Insurance, 1996, page 104.

⁶⁰ See Rosman et al, Issue Brief 3, page 4.

Conclusion

There is now a very strong record that indicates that significant numbers of parents with disabilities and parents with children with disabilities are in the TANF program. The record also indicates that many of these families have been sanctioned and have not received the services and supports they need to succeed. Some of the states, using the flexibility that Congress gave them in 1996 and the TANF funds freed up due to falling cash assistance caseloads, have taken very practical steps to assist these families. The federal legislation should include provisions to ensure that people with disabilities receive the appropriate supports and services to enable them to transition to work successfully.

The National Council on Disability wishes to acknowledge the contributions of Eileen Sweeney, Cary LaCheen, and Celane McWhorter to this paper.