

Introduction

The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA), known generally as “welfare reform,” ended the federal entitlement to public assistance and granted unprecedented autonomy to states to implement welfare reform initiatives. In addition to establishing the Temporary Assistance to Needy Families (TANF) program, the new law set forth a number of important provisions related to issues such as child care, Medicaid, and Supplemental Security Income (SSI).

With funding from the federal Center for Mental Health Services and the Administration for Children and Families, the National Technical Assistance Center for Children’s Mental Health (TA Center) at the Georgetown University Child Development Center is developing a series of resource documents on welfare reform. In particular, our focus has been on how aspects of the law relate to children and families with mental health needs, and to families who are also involved in the child welfare system.

This document is designed as a follow-up to an earlier report produced by the TA Center—*Welfare Reform: Issues and Implications for Children and Families with Mental Health or Substance Abuse Needs*—which discussed key provisions of the welfare reform legislation that were likely to impact children and families with mental health or substance abuse problems. That document also posed a series of “key questions” for states to consider in developing policies that might affect this population.

The current document supplements our first report in several ways:

- It highlights the significance of issues that have emerged during the four years since federal welfare reform legislation was first passed (e.g., the unintended loss of Medicaid by many low-income families);
- It provides an update on relevant provisions of federal welfare reform legislation, incorporating the Final TANF regulations issued by HHS (effective as of October 1, 1999) and the Balanced Budget Act of 1997;
- It provides examples of policies and practices that some states and counties have implemented to assist vulnerable populations in meeting the requirements of welfare reform regulations; and
- It describes a number of major research studies currently underway to examine the impact of various aspects of welfare reform on specific populations.

The report is divided into two chapters. For each major issue discussed, both chapters describe:

- the significance of the issue;
- relevant provisions of the law; and
- practice examples.

Chapter 1 focuses on the significance of the law and practice opportunities for working with low-income families with children who have mental health needs (including families receiving TANF, families transitioning to work, and families whose children no longer qualify for SSI benefits). Key issues that are discussed include:

- TANF time limits and work requirements;
- Child care issues;
- Changes to the Children's SSI program; and
- Access to Medicaid

Chapter 2 focuses on the significance of the law and practice opportunities for working with families receiving TANF who are involved in, or at-risk-for involvement in, the child welfare system. Key issues discussed include how welfare reform legislation affects:

- Children living with relatives;
- Children absent from the home;
- Families with drug and alcohol issues;
- Families affected by domestic violence;
- Teen parents; and
- Fiscal issues

In the fiscal issues section, provisions related to potential funding opportunities and increased flexibility allowed by welfare reform are presented, as well as potential funding constraints for child welfare and other child-serving systems.

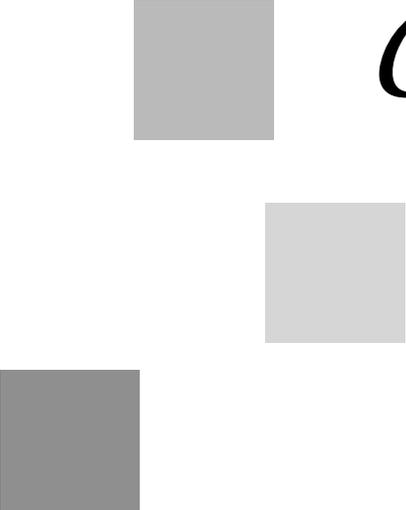
Appendix A of the document describes in detail a number of research studies underway that are examining the impact of changes to the Children's SSI program.

Appendix B of the document includes a Glossary of Terms utilized throughout the report.

It should be noted that there is likely a significant overlap between the groups of families described in Chapters 1 and 2. Numerous recent studies (e.g., Sweeny et al. 2000) have highlighted the fact that families remaining on TANF are likely to have multiple barriers to self-sufficiency, including mental health and substance abuse needs. The intention in separating this document into the two chapters is simply to make the presentation more accessible to readers from multiple fields. Through this discussion, we hope to point out both opportunities and challenges and to stimulate creative ways for service systems to work together to enhance the likelihood for positive outcomes for children and their families.

Reference

Sweeny, Eileen. et al. 2000. *Windows of opportunity: Strategies to support families receiving welfare and other low-income families in the next stage of welfare reform*. Washington, D.C.: Center on Budget and Policy Priorities.



Chapter 1

Making Welfare Reform Work for Parents of Children with Mental Health Needs

Objectives for this chapter are to:

- discuss the significance of key issues—TANF time limits and work requirements, child care, Medicaid, and changes to the SSI program—for low-income parents raising children with emotional or behavioral disorders;
- review relevant provisions of the law; and
- present examples of policy and practice opportunities for assisting families in achieving self-sufficiency while meeting the special needs of their children.

Key Issues

This chapter describes a number of key issues in welfare reform that are important to low-income families with children who have mental health needs (including families receiving TANF, families transitioning to work, and families whose children no longer qualify for SSI benefits). For each major issue discussed, the chapter describe the significance of the issue, relevant provisions of the law, and local and state practice or policy examples.

- **TANF Time Limits and Work Requirements**—TANF time limits and work requirements can pose significant challenges for families of children with emotional or behavior disorders.
- **Child Care**—Finding appropriate, affordable, accessible child care is critical for all families. It is especially important for families on TANF entering the workforce who have children with special needs.
- **Children's Supplemental Security Income (SSI)**—Welfare reform legislation made dramatic changes to the Children's SSI program, significantly reducing eligibility for children with special needs.
- **Access to Medicaid**—Welfare reform legislation separated the link

between financial assistance (TANF) and medical assistance (Medicaid) for low-income families. Although this “de-linking” of TANF and Medicaid was intended to make it easier for low-income families to gain access to Medicaid, there is growing evidence that many are losing health insurance as a result of the new welfare law.

Overview

Changes brought about by recent welfare reform legislation are posing immense challenges to low-income parents, particularly parents who are single and raising children with serious emotional or behavioral disorders. Several aspects of the legislation having a significant effect are:

- The imposition of work requirements and time limits as a condition for the receipt of Temporary Assistance for Needy Families (TANF);
- The ending of federal entitlements to child care assistance and consolidation of all federal child care funds into one block grant;
- A change in eligibility requirements for the receipt of Children’s Supplemental Security Income (SSI); and
- Separation of the link between financial assistance (TANF) and medical assistance (Medicaid) for low income families.

Welfare reform provisions are leading to increasing numbers of parents seeking employment and entering the workforce. However, when parents of children with mental health problems attempt to transition into the workforce, they often face significant barriers and require special support services. Challenges parents face include sustaining employment, finding and maintaining appropriate child care, and ensuring that their children receive necessary health and mental health care services. Therefore, flexibility in the work environment, access to specialized child care, and ongoing access to health and mental health coverage are critical to supporting these families in meeting the challenges of welfare reform.

Significant Statistics

- Among low-income families, the incidence of children with emotional/behavioral disorders is generally found to be about double that of the general population. In a study of current welfare recipients and recent “welfare leavers” in Florida, for example, the percentage of children scoring above a criterion indicating a need for further psychosocial evaluation was twice the rate expected in a general pediatric sample (Boothroyd and Olufokunbi 2000).
- In a study of 753 families receiving welfare in Michigan, 22% of families indicated they had a child with a health, learning, or emotional problem that was a barrier to work. (Danziger et al. 1999.)

- A study of long-term welfare recipients (36 months or more) in Utah revealed that:
 - 29.5% of families reported having at least one child with a learning disability (79% of these children were in special education classes).
 - 23% of families had at least one child with a mental health condition (Child Behavior Checklist scores for the oldest child in the family were in the “clinical” range).
 - 46.3% of families reported that child protective services had investigated the family for child abuse and/or neglect. (Social Research Institute 1999.)
- The Social Security Administration reported in 1998 that children with mental disorders (mental retardation and mental impairments) represented 82% (120,625) of initial terminations after case reviews under the new SSI childhood disability rules. At this point, it is unknown how many of these families will end up seeking TANF assistance to replace lost SSI income. The effect of new disability regulations on families seeking SSI for the first time is also unknown.

TANF Time Limits and Work Requirements

Significance

The TANF work requirements can pose significant challenges for families of children with emotional or behavioral disorders to overcome. First, parents may have difficulty meeting the requirements to work a specific number of hours while receiving TANF because of demands of caring for a child. Second, parents may reach the maximum time limit allowed for receiving TANF before they are able to move into permanent employment (Yates 1999).

Under previous law, most parents raising children with severe emotional or behavioral disorders would have been exempt from work requirements. Welfare reform legislation eliminated any such “categorical” exemptions. While it is possible for a parent who is the caretaker of a child with disabilities to qualify for a hardship exemption, many advocates are concerned that such exemptions will leave families without access to the many supportive services that are being created to assist TANF recipients to achieve self-sufficiency. Many parents would prefer to work if adequate supports were available.

Other issues to consider in designing support services are that when parents, particularly single parents, do enter the workforce, it may be difficult for them to provide adequate care for their child(ren) with emotional or behavioral problems and sustain employment. Children’s conditions can be so time-consuming for parents that they either cannot

Parents’ Voices

“I would love to provide for my own child! My child won’t let me work the way I want to, because I’m called down to the principal’s office 24 hours a day.”

USF, FLORIDA MENTAL
HEALTH INSTITUTE 1999

“...it is hard for parents to keep up with a forty-hour work week, because they are constantly being called to come get their children because they are out of control.”

FEDERATION OF FAMILIES FOR
CHILDREN’S MENTAL HEALTH
MEETING, NOVEMBER 1999

Time Limits

60 months:	28 states
Less than 60 months:	8 states
Intermittent time limits:	6 states
Other:	10 states

find time to go to work on a sustained basis (enough to avoid being fired for excessive absenteeism), or they do not themselves have the stamina to care for their children and maintain work (Yates 1999). In addition, employers may be unable or unwilling to allow the flexibility needed to care for their children and remain in the workforce.

Relevant Provisions of the Law

Time Limits

TANF provisions prohibit states from using federal funds to provide assistance to a family if the family includes an adult or minor head-of-household who has received TANF assistance for 60 months. States have the option to set shorter time limits on the receipt of TANF benefits. Currently, 28 states are using the Federal 60-month time limit; 6 states are using “intermittent” time limits up to a maximum of 60 months over a lifetime (e.g., 24 months on assistance, 24 months off); 8 states are using shorter time limits than 60 months; 5 states are using options involving supplements for families exceeding the five-year limit; 5 states are applying time limits for adults only (HHS 1999).

Exemptions from the Time Limit

States are allowed to extend assistance for up to 20 percent of their caseloads beyond the 60-month time limit. States also have the flexibility to determine which families are not subject to the time limit. If a state opts to extend assistance to a particular family, it may apply the extension only when an adult in the family has received 60 cumulative months of assistance. States can use their own funds, rather than federal TANF funds, to assist in hardship situations that exceed the 20 percent limit.

Among those who may qualify for hardship exemptions from the 60-month time limit are individuals with a physical or mental disability or individuals caring for a family member with a disability. However, many states have not yet determined who will receive hardship exemptions, and until that time are opting to consider everyone subject to the 60-month time limit on federal assistance (HHS 1998).

Work Participation

Immediate work participation:	20 states
Participation within 45 days to 6 months:	6 states
Participation within 24 months:	23 states
Other time frames:	2 states

Work Participation

States must require TANF recipients to participate in work activities (as defined by the state) when they are determined ready, or within 24 months of entering the TANF caseload. States have the option to impose work requirements sooner than 24 months. Currently, 20 states require immediate participation in work; 6 states require participation in work between 45 days and 6 months of receipt of cash assistance; 23 states require participation within 24 months; and 2 states within other time frames (HHS 1999).

The immediate work participation requirement of 20 states has significant implications for parents of children with disabilities. Adequate services, supports, and child care are needed to accomplish this.

Sanctions

States are required to sanction individuals who fail to meet specified work requirements. The state has the option to either reduce or terminate cash benefits for the family, and also to terminate Medicaid for the adult who fails to meet the work requirement. Unfortunately, families with the most barriers to employment are the most likely to be sanctioned for failure to meet work requirements. Many of these sanctioned families have substance abuse or mental health problems.

Fourteen states reduce the amount of cash assistance when a family is sanctioned; 37 states impose a maximum sanction for refusing to comply with work requirements, which results in a loss of all cash assistance. In most of these states, however, the total loss of cash assistance results after several instances of noncompliance (HHS 1999).

Sanctions

Reduced cash assistance:
14 states

Loss of ALL cash assistance:
37 states

PRACTICE EXAMPLES

Working with Families Struggling to Meet TANF Work Requirements

As seen in the statistics above, many parents who seek welfare assistance may be subject to work requirements very shortly after they begin receiving TANF. In some communities, cross-system collaborative strategies are being utilized to assist families who face barriers to employment, including families raising children with emotional or behavioral problems.

- **Washington State** has initiated a pilot program known as the *WorkFirst Public Health Partnership for Children with Special Needs*. This program provides in-home nursing evaluations of children with special medical, developmental or behavioral problems in order to assist the state TANF agency in determining a participant's level of ability to take part in WorkFirst activities. Public Health Nurses (PHNs) assess the impact of the child's special needs on the parent's ability to seek and maintain employment. If the child's age is from birth to 3 years, the nurse ensures that the parent has contacted (or contacts for the family) the local Family Resources Coordinator. The Family Resources Coordinator assists the family in developing an Individualized Family Services Plan and accessing early intervention services.

Public Health Nurses and caseworkers have the flexibility to work with the participant on a plan of activities that meets the needs of the family. For example, hours that a parent spends taking a child to therapy appointments, working in the child's classroom, or educating childcare providers about a child's special needs can be counted towards the TANF work hour requirement.

- In **Ventura County, California**, CalWorks offices are set up utilizing the "one stop shopping" or "co-location" model. Multiple services and access to service providers are available within the same office. PHNs are available to conduct home visits for TANF families in order to conduct developmental assessments or evaluate the psychosocial needs of children whose parents are struggling to meet work requirements. The PHNs work with parents on parenting skills, interface with the child's school when a child is having difficulties, and work with parents and the TANF caseworker on a work plan. Countable work activities during this period may include getting a parent to participate in the child's classroom or Head Start. No parent is sanctioned during the period when the PHN is assisting the parent in developing a work plan.

Continued

PRACTICE EXAMPLES *Continued*

- In **Tennessee**, the “Customer Service Review” is a practice instituted by the Tennessee Department of Human Services to examine all cases scheduled to be closed due to noncompliance with the Families First welfare reform program. Prior to case closure, each family’s situation must be reviewed to assess the appropriateness of an action taken by the case manager. Case managers are also required to make several attempts to contact the welfare recipient prior to issuing a sanction. As part of this case review, PHNs also visit the family to determine whether they have special needs.

Child Care Issues

Significance

More and more families whose children have special needs are entering the work force or being subject to work requirements in order to receive TANF assistance. Finding appropriate, affordable, accessible child care has been a barrier for all families, but placements for children with special needs are consistently reported as being even more difficult to find. These placements are also more expensive to families and to states that are subsidizing child care.

Relevant Provisions of the Law

Legislation in the PRWORA concerning child care made the following changes:

- Ended the federal entitlement to child care for families receiving cash assistance, families transitioning from welfare to work, and families at risk of needing welfare if child care assistance was not provided.
- Consolidated federal child care funding for families on TANF and low-income working parents into a single block grant, the Child Care and Development Block Grant (CCDBG).
- Allowed states to transfer up to 30% of their TANF allocation to their CCDBG.
- Prohibited states from sanctioning (reducing or ending TANF assistance) single parents of children under age 6 who have a “demonstrated inability” to find child care.
- Allowed states to provide **transitional child care assistance** to families leaving TANF for work.

States vary in the length of time families are eligible to receive transitional child care assistance. The Federal law allows states to provide families with 12 months of transitional child care assistance, but 33 states have opted to extend transitional child care for longer than 12 months for families moving off of welfare (HHS 1999).

Transitional Child Care Assistance

Federal Law allows:
12 months

States opting to extend
beyond 12 months:
33 states

TANF Final Regulations issued by HHS made several clarifications regarding child care issues:

- The TANF Final Regulations narrowed the definition of what counts as “assistance” for a family, and child care for working families is **excluded** from this definition. This is significant in that it allows states to use TANF funds to provide child care for these families without them being subject to TANF time limit, work participation or child support requirements. Therefore, it may be less necessary for states to transfer funds to the CCDBG in order to avoid TANF restrictions being placed on working families who receive child care assistance but not TANF cash assistance.
- Welfare reform legislation imposes a penalty on states for violating the prohibition on sanctioning families who are unable to find child care for a child under age 6. The state TANF agency is charged with defining relevant terms (e.g., what is **adequate** or **accessible** child care), as well as informing parents about the state’s procedures for determining a family’s inability to obtain child care (including appeal procedures). This is a change from the proposed TANF regulations which only required that the state child care agency, rather than the TANF agency, provide such information (Schott et al. 1999).

A few states have extended the federal exception to work requirements for single parents unable to find child care. In these states, parents with children older than age 6, who are unable to find child care, are not sanctioned. However, families are still subject to the 60-month time limit on TANF during this period.

California regulations specify that a family cannot be sanctioned for failure to find adequate child care if the child is under age 10.

New York TANF child care regulations specify that *caretaker relatives* cannot be sanctioned for failure to find adequate child care for a child who is under age 13.

States have been encouraged to examine whether there is an adequate statewide process to inform parents about this exception to work requirements for single parents unable to find child care. The final TANF regulations described criteria that HHS will consider in determining the amount of the penalty to be imposed on states that, in violation of federal law, sanction a single parent, caring for a child under age 6, who demonstrates an inability to obtain child care. Among these considerations are whether the state has a statewide process to inform parents about this exception to the work requirements.

Advocates in New York City successfully sued the city for not providing adequate information to families about the exception to work requirements for families unable to find adequate child care. Following this, the State sent all counties transmittals reminding them of the federal and state law protections for families unable to find child care. The transmittals also instructed local districts to provide a notice to every TANF applicant and recipient informing them of their rights about child care (NOW Legal Defense and Education Fund 1999).

PRACTICE EXAMPLES

Access to Child Care for Children with Special Needs

Access to Subsidized Child Care

Some states are providing families of children with special needs priority access to subsidized child care. Many states are unable to fund child care for all families meeting federal eligibility criteria for subsidized child care (these include families on welfare, families transitioning off welfare, and working poor). To allocate limited resources, states are controlling access to their child care programs through various state-defined criteria or by the manner in which they distribute subsidies to families (GAO 1998).

- In **Massachusetts, Iowa and Tennessee**, children with disabilities or special needs have priority in terms of access to subsidized child care.
- Some states such as **New York and Texas** are maintaining a child care subsidy guarantee for all public assistance recipients engaged in work and transitioning from public assistance.

The problem with all of these strategies, however, is that in a situation of limited resources, prioritizing any population for receipt of subsidies necessarily reduces access to services in another population, e.g., the working poor. Therefore, states should be encouraged to engage in activities to increase the supply of child care providers, particularly for children with special needs.

Increasing the Supply of Child Care Providers Able to Care for Children with Special Needs

States and communities have utilized the following strategies to increase the number of child care providers who are willing to care for children with special needs, including children with emotional or behavioral disorders:

- providing higher payments to providers (e.g., **Washington State** reimburses providers an additional 30% when they care for a child with special needs)
- providing access to additional training for child care providers (see “Training TANF Recipients to Become Child Care Providers” below)
- obtaining technical assistance for state and local child care planning

Technical Assistance Resource: “Map to Inclusive Child Care”

The federal Child Care Bureau awarded a contract to provide technical assistance to 10 states in the development and implementation of state plans aimed at improving and expanding their child care service delivery system for children with disabilities. The contract was awarded to the United Cerebral Palsy Association with six subcontractors: the University of Connecticut Health Center; the National Conference of State Legislatures; the National Child Care Association; the Federation of Children with Special Needs; the National School Age Care Alliance; and Zero to Three. States selected to receive technical assistance during year one of the project were: Vermont, New Jersey, Maryland, Tennessee, Indiana, New Mexico, Iowa, Utah, California and Oregon (American Academy of Pediatrics 2000).

Mental Health Consultation to Child Care Providers

Another strategy aimed at assisting child care providers in maintaining children with emotional or behavioral problems in child care placements is known as *mental health consultation*. In this practice, mental health experts provide consultation to providers around strategies for working with individual children who might otherwise be kicked out of their child care placement (Cohen and Kaufmann 2000).

- In **Vermont**, the state is allocating Child Care Development Block Grant funds to help integrate children with special needs into child care centers, and to provide mental health consultations for these children.

PRACTICE EXAMPLES

Child Care Resource and Referral Agencies

Increasingly, many states are utilizing Child Care Resource and Referral agencies (R&Rs) to assist families in identifying placements for children with special needs.

- In **Washington**, the Department of Social and Human Services (TANF agency) has contracted with the Child Care Resource and Referral Agencies of Washington State to enhance services for families who need child care for children with special needs. Services include referrals to providers with the necessary skills and training to care for children with special needs; training providers to care for children with special needs; and recruitment of child care providers for special need populations.
- In **Tennessee**, funds supporting Resource and Referral activities will be used to create a network of Child Care Resource Centers across the state to assist providers to improve their programs or practices and to successfully include children with special needs.
- In **Iowa**, Healthy Child Care Iowa has placed health consultants in Resource and Referral agencies through a contract with the Iowa Department of Public Health.

Training TANF Recipients to Become Child Care Providers

Some states and localities, as well as non-profit organizations, are providing training for TANF recipients to themselves become child care providers. Enhanced training may be available to enable these women to provide care for children with special needs.

- In **Arkansas**, “Early Childhood Training,” a grant to the University of Arkansas for Medical Sciences, is being used to teach women on TANF how to work in the child care field. Training is provided through subcontracts with a number of sites, including Arkansas Easter Seals, which provides training around working with children both with and without disabilities. Easter Seals utilizes certified teachers with masters degrees in early childhood special education. The aim is to increase awareness of different disabilities, developmental challenges, and behavioral issues. The grant covers child care for training recipients.
- The Lincoln Action Program (LAP), based in **Lincoln, Nebraska**, has designed the Job Opportunities for Low-Income Individuals (JOLI) Project to address the dual need for employment and child care among welfare recipients and other low-income people. In addition to providing case management, JOLI offers welfare recipients training and support in establishing an in-home child care business. The program provides, at no cost to the participant, more than 50 hours of training in child care-related skill development as well as business management. The case management services are provided to reduce any existing barriers to self-sufficiency and successful business operation. Family strengths and barriers are identified through a comprehensive assessment.

Program participants are encouraged to consider receiving additional training that would allow them to accept children with special needs. If a parent expresses interest in this area, they are referred to the city/county Health Department which provides special needs child care training at no charge. This enables the parent to accept fewer children at a higher rate of pay.

- The Child Care Support Center in **Atlanta, Georgia**, designed Child Care Solutions (CCS) to help parents find child care in the metropolitan Atlanta area. The Child Care Support Center is familiar with

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PRACTICE EXAMPLES *Continued*

the unique needs of the welfare-to-work population and seeks to address those needs through specialized programs and through coordination with the Atlanta Department of Family and Children's Services. The center has two goals: (1) to strengthen the ability of families, caregivers, and communities to nurture, support, and educate all children; and (2) to build a supply of affordable, high-quality child care in 16 metropolitan Atlanta counties.

CCS is a child care resource and referral service that provides information, assistance, and training to caregivers and educates parents and the community about the importance of expanding affordable, high-quality child care (with special attention given to nonstandard hours care, sick-child care, and *special-needs child care*). CCS maintains data on child care facilities and family child care homes that can offer specialized care for children with disabilities. While CCS is provided to all residents of Greater Atlanta, its counselors spend substantial time providing child care counseling to the growing number of welfare recipients making the transition to work.

Caregivers who wish to be listed with CCS fill out an application form that details their training and experience with children with special needs. CCS uses "Care Finder" which lists attention deficit disorders, learning disabilities, emotional disturbances, respite care, etc. as areas for providers to describe the training and experience they have. Staff of CCS also provide training to family day care providers who are interested in obtaining skills that would enable them to care for children with special needs.

For more information on inclusive child care, see the federal Child Care Bureau web page at www.acf.dhhs.gov/programs/ccb.

Children's Supplemental Security Income (SSI) Program Changes

Significance

Welfare reform legislation made dramatic changes to the Children's SSI program, significantly reducing eligibility for children with mental or emotional disorders. Under the new law, there are three major changes in the eligibility standards:

- Children must qualify under a new definition of childhood disability.
- Children are no longer able to qualify through the eligibility mechanism known as the "individualized functional assessment" (IFA).
- References to "maladaptive behavior" in the medical listing of impairments have been eliminated.

As changes in the children's SSI program are implemented, certain critical concerns are emerging. These issues include the following:

- **How are children with mental impairments faring under the new definition of disability, which requires proof of a higher level of severity?**

The highest percentage of children reviewed under the new disability standard were those with mental retardation or mental impairments because they were typically evaluated using the IFA. It is important to track children now applying for SSI who have mental and emotional disorders to see how many are approved.

- **Are states identifying children who are losing SSI? If so, are they tracking them to determine who may apply for and receive TANF assistance?**

The financial impact on families whose children lose eligibility for SSI benefits will be significant. Many SSI-eligible children live in single-parent households where the mothers report that the time-consuming nature of their children's impairments interferes with their ability to enter the work force. Some of these families may qualify for cash assistance through the TANF program although the parents will face new work requirements and will be eligible only for time-limited assistance.

- **Are states providing financial assistance to the families of children losing SSI benefits?**

The American Public Welfare Association (now American Public Human Services Association) conducted a survey during the summer of 1997 to determine how states might respond to various changes mandated by the new welfare legislation. At that time, only 6 states indicated that they might offset the loss of SSI income (APWA 1998).

Relevant Provisions of the Law

Federal Welfare Reform Legislation

- **Established a new definition of childhood disability with higher standard of severity required**

To qualify for SSI, children under age 18 will have to meet a higher, stricter definition of disability than was previously required. This new standard requires that a child's physical or mental impairments will result in "severe and marked functional limitations", which can be expected to result in death or which have lasted (or can be expected to last) at least 12 months.

The Social Security Administration (SSA) maintains a "Listing of Medical Impairments". To be eligible for SSI now, a child must have an impairment that is medically or functionally equal to or more severe than a condition in the Social Security Administration Listing.

- **Eliminated the eligibility mechanism known as the “individualized functional assessment”**

The new law requires SSA to discontinue use of the “individualized functional assessment” (IFA) which was developed to implement the U.S. Supreme Court *Zebley* decision. *Zebley* required SSA to develop an eligibility mechanism to evaluate children’s functional limitations beyond SSA’s narrow medical listings. Many children with mental retardation and mental impairments qualified under the IFA because it was an easier way for disability examiners to evaluate the impact of their condition. Note that the new definition of childhood disability still requires disability examiners to assess functional limitations, but children must show a higher level of severity to qualify.

- **Eliminated use of the term “maladaptive behavior” when evaluating children’s mental impairments**

Prior to the welfare reform legislation, evidence of maladaptive behavior was included in the childhood mental impairment listings in the personal/behavioral area of functioning. Although the legislation removes specific references to “maladaptive behavior” from the listings, this type of behavior still indicates a possible impairment and is evidence for disability examiners to consider during the evaluation process.

- **Required mandatory eligibility reviews for certain children who were receiving SSI at the time of program changes**

SSA notified over 260,000 children who were potentially affected by SSI childhood disability program changes that their cases would be re-evaluated under the new law. To determine they still qualified for SSI benefits, SSA reviewed cases of children who had been found eligible for SSI through an individualized functional assessment. They also reviewed cases that involved consideration of “maladaptive behaviors” in the personal/behavioral area of childhood mental impairment listings.

- **Requires mandatory disability reviews of children when they reach age 18**

Using the adult disability standard, SSA will re-determine the eligibility of children who are eligible for SSI when they reach age 18.

State Policy Options Related to SSI Issues

- States may allocate their own funds for children losing federal SSI cash assistance or provide alternative sources of financial assistance.
- States may identify children living with families receiving TANF cash assistance who may meet the new definition of childhood disability and qualify for federal SSI benefits.
- States may examine the population of young people losing SSI benefits at age 18 when their disability is re-evaluated under the adult

disability criteria. Among the issues that states may want to address are whether these young people are receiving appropriate vocational rehabilitation services and other transition services before they reach age 18.

- SSA is required to refer all SSI-eligible children under age 16 to the state Title V/Maternal and Child Health agency. The Title V agency may provide or arrange for rehabilitation services for SSI-eligible children to the extent that these services are not covered by Medicaid.
- SSA is required to refer all SSI-eligible individuals to the state vocational rehabilitation agency starting at age 16.
- Children who qualify for special education services through the Individuals with Disabilities Education Act (IDEA) have an individualized education program (IEP). Under the 1997 IDEA Amendments, beginning at age 14, a student's IEP must include a "statement of the transition service needs." At age 16, the student's IEP must include a statement of needed transition services.
- States can work to inform families about the legal responsibility of different state agencies to provide assistance as children transition from school to work.

RESEARCH: Studies Tracking Children's SSI Program Changes

A number of long-range studies are underway to evaluate the impact of changes in the children's SSI program. The studies are being conducted by:

- University of South Florida, Florida Mental Health Institute
- Congress/General Accounting Office
- Social Security Administration
 - Office of Disability/American Association of University Affiliated Programs for Persons with Developmental Disabilities
 - Mathematica Policy Research, Inc.
 - Rand Corporation

A brief description of each of these studies is provided in **Appendix A**. Although the studies vary in their specific objectives and methodologies, all have some significance for families raising children with mental, emotional and behavioral disorders because this group represents the largest group affected by the legislative changes to SSI.

PRACTICE EXAMPLES

The State of **Maryland** screens TANF applicants for potential referral to SSI, and is working to expand access to SSI for children, in TANF families or elsewhere, in part to stem the use and cost of foster care. A state-funded contractor—Disability Entitlement Advocacy Program (DEAP)—assists families in applying for SSI and continues as long as the SSI determination is pending. During this time the TANF time clock stops, the case is funded with state MOE dollars in a separate state program, and other services may continue (Kramer 1999).

In **Michigan**, early intervention advocates within the Department of Education were able to obtain 3-month work deferrals for parents on TANF whose children are involved in “Early On” (a program for children age 0-3, funded by Part C of IDEA). They were successful in getting the legislature to approve this by explaining the link between the recognized need for work deferrals for parents’ whose children were on SSI and the fact that very young children might not yet have a diagnosis that would qualify them for SSI. Early On staff advocate for the work deferrals within Michigan’s Work First program. The deferrals are designed to give families more time to search for adequate day care.

Access to Medicaid

Significance

Welfare reform legislation separated the link between financial assistance (TANF) and medical assistance (Medicaid) for low-income families. The legislation set Medicaid eligibility at AFDC criteria that were in effect on July 16, 1996. Therefore, a family who qualified for Medicaid under the AFDC income eligibility criteria generally would qualify for Medicaid under the TANF block grant. The legislation also allows states greater flexibility to expand Medicaid coverage to greater numbers, if the states wish to do so. This provision includes expanded coverage to two-parent working families. Another option that states have is to extend free or affordable medical coverage to low-income uninsured children is through Title XXI of the Social Security Act—the State Children’s Health Insurance Program (SCHIP), enacted in 1997.

The “de-linking” of TANF and Medicaid was intended to make it easier for low-income families to gain access to Medicaid; however, there is growing evidence that hundreds of thousands of people are losing health insurance as a result of the new welfare law. The problem is described as “pervasive” by federal and state officials and health policy experts. The United States General Accounting Office (1999) reported that the declines in Medicaid are similar to those seen in TANF. In theory, however, the number of individuals enrolled in Medicaid should be increasing due to expansion efforts and broader eligibility. The only situation that would warrant a decline in Medicaid enrollment would be increases in income, which has not proven to be the case. Several studies have documented the extent of the problem. These include:

- Families USA Foundation—*Losing Health Insurance: The Unintended Consequences of Welfare Reform*, 1999. (Available at www.familiesusa.org).
- Kaiser Family Foundation—*Participation in Welfare and Medicaid*, by Mark Greenberg, 1998. (Available at www.kff.org).

The loss of Medicaid can be particularly catastrophic for families in which a child has a disability such as a serious emotional disturbance, since many of these families rely on Medicaid to cover treatment services. Although some studies are tracking the number of families who lose Medicaid when they lose TANF assistance, these inquiries devote little attention to the special impact on children with disabilities. It is important to track this group of children because some may qualify for SSI, which in most states provides automatic eligibility for Medicaid. Furthermore, states have a legal obligation to continue Medicaid eligibility for all recipients while determining if they qualify under any possible eligibility category.

Relevant Provisions of the Law

Section 1931 of the Social Security Act

- **Eliminates automatic link between Medicaid eligibility and welfare cash assistance**

Prior to the passage of welfare reform legislation, families that qualified for welfare assistance (AFDC) were automatically enrolled in Medicaid. Welfare reform legislation created a new eligibility category—Section 1931—which allows families to qualify for Medicaid if they meet the AFDC eligibility standards that were in effect on July 16, 1996. The statute *requires* that eligibility for each program be determined *independently*. Therefore, a family that may not qualify for TANF may still qualify for medical coverage under Medicaid because of the differing eligibility standards between the two programs.

- **Provides states with greater flexibility to expand Medicaid coverage**

Section 1931 allows states to expand Medicaid coverage beyond the minimum federal requirements set by AFDC eligibility standards. States have the freedom to expand Medicaid to cover more low-income families, as well as to cover more two-parent working families. When states expand Medicaid coverage to families at higher income levels, the families remain eligible for coverage as long as their income does not exceed the set threshold and they continue to meet other requirements.

Transitional Medicaid Assistance

- **Provides access to Transitional Medicaid Assistance for families who leave welfare to enter the work force**

States must provide extended Medicaid benefits to families who lose their eligibility for Medicaid under Section 1931, for example when

they enter the workforce and have income higher than that allowed under Section 1931. Transitional Medicaid Assistance (TMA) is *not triggered by the loss of TANF* income assistance, only by the loss of *Medicaid* coverage under Section 1931. TMA must be provided in the initial six months after the loss of coverage. An additional six months can be granted based on certain reporting requirements and income limits. In order to qualify for TMA, a family must have received Medicaid for at least three out of the previous six months.

Medicaid Regulations

■ Right to apply

Medicaid regulations require that states provide the opportunity for families to apply for Medicaid **without delay**. States may not impose a waiting period before providing the application for Medicaid or processing it.

■ Requires state Medicaid agencies to continue eligibility for all recipients while determining if they qualify under any other eligibility category

Federal Medicaid law requires state Medicaid agencies to continue eligibility for all recipients while determining if they qualify under any other eligibility category, even if the family does not request continued coverage. Children whose families no longer receive cash assistance may still qualify for Medicaid based on their family income and age. Under federal law, certain children qualify through what are commonly called “poverty level” eligibility categories, including:

- Children below age six living in families with incomes up to 133 percent federal poverty level (FPL).
- Children ages 6-14 living in families with incomes at or below 100 percent FPL.
- By federal law, all children under age 19 living below the poverty line will be Medicaid eligible by 2002. (Under this provision, coverage is being phased in one year at a time.)
- States are allowed to provide coverage to children beyond the mandatory categories.

■ Timely response

Eligibility must be determined for most families in 45 days from the date of application. Even if a family does not qualify for TANF, a timely decision on Medicaid eligibility must be made.

State Options in the Law

■ States may offer Medicaid eligibility to children for a period of 12 continuous months

States may provide 12 months of continuous Medicaid coverage for children without regard to any changes in family circumstances that might otherwise affect ongoing eligibility. States choosing this option,

provided by the Balanced Budget Act of 1997, do not have to conduct a Medicaid redetermination for children when the family no longer qualifies for TANF assistance.

- **States have the option to extend Transitional Medicaid Assistance for longer time periods**

According to Guyer and Mann (1998) a dozen states have received waivers to do this.

- **States may offer presumptive Medicaid eligibility for children**

Using preliminary information, children may receive temporary Medicaid eligibility if their family income falls within the state's eligibility income limits. Only certain entities are permitted to make presumptive eligibility determinations for Medicaid.

- **States have the option to terminate Medicaid for an adult (or teen head of household) under TANF work-related sanctions**

As of February 2000, 13 states had exercised the option to terminate Medicaid coverage of a non-pregnant adult who loses TANF for failure to work (State Policy Demonstration Project). Although states have the authority to impose this sanction, it cannot be extended to other family members or to pregnant women, or for reasons other than failing to meet work requirements. The state can terminate Medicaid benefits for a teen head of household for failing to meet TANF requirements.

- **State Children's Health Insurance Program (SCHIP)**

The Balanced Budget Act of 1997 created Title XXI, the State Children's Health Insurance Program, to provide capped matching funds to states that want to expand health insurance to low-income children who do not qualify for Medicaid. States have the option to expand Medicaid, create a new health insurance program, or develop a combination of the two. However, states must check for Medicaid eligibility before enrolling a child in the SCHIP program.

State-Level Strategies Related to Medicaid

- **States may expand Medicaid coverage beyond the minimum federal requirements** established in Section 1931, which replaced the previous automatic eligibility link between welfare and Medicaid.

- **States may expand the group of children who qualify for Medicaid** through the mandatory poverty-level categories by accelerating the phase-in or raising the income eligibility level beyond the minimum. As of October 1998, over 40 states and the District of Columbia had expanded coverage for children.

- **States may expand Medicaid for children through their new SCHIP programs**, as described above.

As of 2000, HCFA reports that 23 states/territories are using Title

Extended Time Period for TMA

12 States

Using Medicaid Termination Option

13 States

Expanded Medicaid Coverage to More Children

Over 40 States

Children's Health Insurance Program

Expanding Medicaid:
23 states

Separate program:
15 states

Combination program:
18 states

XXI to expand Medicaid; 15 for a separate state health insurance program; and 18 for a combination of the two. States have the option to amend their SCHIP plans, and a number of states have already done so or intend to do so. As a result of plan amendments, states may continue to expand eligibility for uninsured children as they gain more experience administering their SCHIP programs.

For more information about SCHIP state plans, visit the Web site for the Health Care Financing Administration, the federal agency that is responsible for the program, at www.hcfa.gov.

- **States can coordinate the administration of their TANF and Medicaid programs to ensure ongoing eligibility.**

States have the responsibility to establish and maintain Medicaid eligibility for families and children affected by changes in the welfare law. In a letter sent to TANF Administrators and State Medicaid Directors, dated June 5, 1998, the U.S. Department of Health and Human Services described this responsibility. In a subsequent letter, dated March 22, 1999, HHS included the guide, *Supporting Families in Transition: A Guide to Expanding Health Coverage in the Post-Welfare Reform World*, to explain the various state options and to suggest ways to ensure that TANF programs are informed about Medicaid and SCHIP and enrolled when eligible. Both letters and the guide are available at the HCFA Web site at www.hcfa.gov/audience/states.

- **States can utilize funds from the “\$500 million fund” for administrative purposes.**

A fund was developed through the welfare reform legislation to aid states in implementing the de-linking of Medicaid and cash assistance. This fund is intended for administrative purposes. Some states have used some of their money to train eligibility technicians on the Section 1931 eligibility category; establish outstation sites in hospitals, health centers and schools; hire staff to liaison between TANF and Medicaid offices; develop outreach campaigns that target African-American and Hispanic communities; conduct broad-based media campaigns; develop new computer systems; and send notices to families.

The matching rate for the fund ranges between 75 percent and 90 percent. This fund was due to “sunset” on October 1, 2000. However, national and state specific expiration dates for the availability of allotments for state expenditures under the \$500 million fund have since been removed. Each state's allotment of the \$500 million is now available until it is expended by the state (HCFA 2000).

- **States can work to inform families about the on-going availability of Medicaid and the new State Children's Health Insurance Program (SCHIP).**

Families in a variety of circumstances lack information about their on-going eligibility for Medicaid or SCHIP. These include families who

are denied, diverted or terminated from TANF; families whose children lose their SSI benefits; working families who may have no contact with the welfare office, but whose income is low enough to qualify them for SCHIP. States can conduct aggressive outreach to provide Medicaid and SCHIP information to all low-income families.

States can consider adopting a number of policies that would encourage and support greater outreach to families whose children are potentially eligible for Medicaid or SCHIP. These options include:

- Providing Medicaid and SCHIP outreach to families at TANF sites.
- Placing Medicaid and SCHIP workers in TANF offices.
- Placing Medicaid and SCHIP eligibility workers in communities.
- Improving the availability of application sites.
- Creating application sites outside the welfare office.
- Simplifying the application and enrollment processes.
- Educating families about different programs, including transitional Medicaid.

Information Resources

- The Center on Budget and Policy Priorities runs the *Start Healthy, Stay Healthy Campaign* that helps service providers, program administrators and community-based organizations to identify children who may qualify for free or low-cost health insurance programs. The Campaign also promotes coordination between SCHIP and Medicaid to ensure that children do not lose their coverage. The Campaign produces an outreach kit, which includes a handbook with fact sheets and ideas for creative outreach strategies; posters and flyers; and an Income Eligibility Screening Tool that can help identify children who may qualify for various health insurance programs. The kit is available, for a small fee, by contacting the Campaign at www.cbpp.org/shsh/index.html.
- The Families USA Foundation recently published a resource guide for health advocates at the state level to help address many of the previously stated problems. The guide, *What Did Welfare Reform do to Medicaid in Your State and What Can You Do About It? An Action Kit for Advocates*, provides an overview of the changes in the Medicaid program as a result of welfare reform legislation and well as tools to identify the problems in individual states and how an organization can best influence change. Its stated objective is to help “health advocates to develop strategies and campaigns to address problems that are leading to Medicaid declines or illegal Medicaid practices in your state.” The kit addresses three broad areas that have been noted as problematic with the change to the Medicaid program: applying for Medicaid, keeping Medicaid and reaching new families. The document is available on the Families USA web site at

www.familiesusa.org/actkit.htm. Contact information for this kit: Rachel Klein or Bill England at Families USA, 1334 G Street, NW, Washington, DC 20005, 202/628-3030.

Research on the Impact of Medical Assistance Program Changes on Special Populations

Although there is concern about whether changes in the new welfare law affect children's access to Medicaid, there is little specific attention in research studies to the repercussions for children with disabilities. One notable exception is a study funded by the **Health Care Financing Administration (HCFA)**.

- **Contractor:** Mathematica Policy Research, Inc.
- **Objective:** evaluate whether medical assistance continues or changes for different sub-populations affected by 1996 welfare legislation—children with disabilities; immigrants; individuals with addiction disorders; individuals formerly eligible for AFDC.
- **Scope:** Children with disabilities are part of this comprehensive study. The study will examine Medicaid eligibility, utilization and expenditure patterns for children who continue to qualify for Medicaid as well as those who lose it as a result of losing their SSI eligibility. The study, based on data from 1996-1998 from ten states, will include children who continue to qualify for SSI as well as those who do not. A special focus, using data from three states, will examine the impact on children with mental and behavioral disorders to determine how their Medicaid eligibility status affects expenditures for their mental health services.
- **Methodology:** HCFA has an interagency agreement with the Social Security Administration (SSA) to develop and use SSI and Medicaid linked data to examine the effect of legislative changes on Medicaid/SSI enrollees. For the study populations, the Supplementary Security Record and the Disability Determination file (often called the "831 file") and the State Medicaid Research Files (SMRF) will be used.
- **Contact:** Penelope Pine, Office of Strategic Planning/Research and Evaluation/Division of Beneficiary Research, 410-786-7718, Ppine@hcfa.gov.

For more extensive information on Medicaid and welfare reform, the following documents are available via the Web:

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