



SECTION 6

SUMMARY AND IMPLICATIONS

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The SSI Family Impact Study examines the impact of a major policy change in a program designed to provide economic assistance to low-income families with children who have a serious emotional or behavioral disorder. Study findings have implications that are applicable to federal, state and local policymakers, evaluators and the family advocacy support movement. Also, in October 1998, the National Technical Assistance Center for Children's Mental Health at Georgetown University Child Development Center released a report, *Welfare Reform: Issues and Implications for Children and Families Who Need Mental Health or Substance Abuse Services*,¹ which posed a number of *Key Questions* that mental health, substance abuse, child welfare and family organizations might wish to consider about Welfare Reform and SSI. The families who shared their stories for this study helped provide some answers to those questions, which are noted throughout this section.

● Importance of the inter-relatedness of supports

It became evident throughout the study that SSI is part of a larger, complex, inter-related system of support for families with low-incomes who have children with mental health needs. When SSI was removed, other areas of support were affected as well, such as access to Medicaid. The changes in SSI, in turn, were part of a larger reform effort in welfare. Welfare reform had direct effects on employment through TANF work requirements, on child care, and on access to health care as the reform legislation de-linked Medicaid (medical assistance) and TANF (financial assistance). A growing body of research is showing that the federal welfare reform effort appears to have resulted in unintended reductions in Medicaid enrollment among children.²

● Importance of services and supports for children with emotional/behavioral disorders

The SSI changes were a policy decision, not a diagnostic one. The change in eligibility or SSI status for these children did not change their need for services. While the study did not involve direct assessment of the children, these children appeared to have significant emotional disturbances, and a continued need for services from public systems. Thus, while savings may have accrued to the SSA as a result of the SSI changes,³ these children and families continued to use other public services and supports, such as special education. It is becoming evident that Medicaid service utilization data for the SSI population picks up only a fraction of service use by children with special needs because many of these children no longer qualify for SSI, even though they have serious disorders

The SSI Family Impact Study supports the conclusion that the "breadth of research findings now emerging largely as a result of welfare reform suggesting that a substantial subset of families will need episodic or sustained help much longer than TANF time limits will allow, from a broader array of providers than TANF agencies consistently or effectively interact with, and that some may need help from outside the TANF system entirely."

Kramer (2000)⁴

¹ Woolverton, M., Wischmann, A., McCarthy, J., & Schulzinger, R. (1998). *Welfare reform: Issues and implications for children and families who need mental health or substance abuse services*, National Technical Assistance Center for Children's Mental Health, Georgetown University Child Development Center, Washington DC.

² Garrett, B. & Holahan, J. (2000). Health insurance coverage after welfare. *Health Affairs* 19 (1), 175-84.

³ It has been estimated that changes in eligibility will result in an \$8 billion cut to SSI over the next six years, Lizbeth Boroughs, Director of Legislative Affairs explained on July 15, 1997, "Welfare Legislation."

⁴ Kramer, F. D. (2000). Research on children, families, and the New Federalism: Seeing TANF from the inside out—Reconsidering the programs' role in the wake of welfare reform. *The Forum*, 3(2).

KEY QUESTION: What information is available and/or process in place to help families appeal if their child loses SSI benefits after re-determination under the new rules?

ANSWER: *According to families, there was not much information accessible to families. Families reported seeking information about the appeal from the 1-800 number provided in the re-determination letter they first received or from the local SSA office. Most reported they were unable to speak with a 'live' person on the 1-800 number, or were not able to get through. Those that went to the local SSA office for information were also met with long waits and/or confusing or inaccurate information. The few families who sought help from Legal Assistance were discouraged, often being transferred from one person to another with little follow-through.*

KEY QUESTION: Do school, mental health, child welfare, and family/advocacy organizations in the community have staff who can provide assistance to families in understanding the new SSI eligibility regulations and the re-determination and appeals process?

ANSWER: *No. Families reported seeking help from many different agencies, including school and mental health organizations, and received little help from any. If information was obtained, it was often misleading or inaccurate.*

KEY QUESTION: Who is responsible for communicating with families whose children lose SSI about continued Medicaid eligibility? How are parents assisted in this Medicaid application process?

ANSWER: *From the parents' perspective, it appeared no one was responsible. However, under federal law, before Medicaid stops providing medical assistance, it must review the child's case for eligibility for any other reason. This review, however, is reportedly not done by all Medicaid agencies. Thus, it is the family's responsibility to call the state Medicaid agency to see if their child can qualify for Medicaid for other reasons. Parents reported very little help with this process.*

and are heavy users of services. A recent analysis of Medicaid expenditures found that among child and adolescent “high cost” users of mental health and substance abuse service paid for by Medicaid, only one third were SSI recipients.⁵

● Importance of communicating policy changes

Many of the study's findings reflect the importance of an effective process for communicating legislated program changes. According to families, programs were unable to provide them with accurate and complete information. Misleading, inaccurate or inadequate information caused many families to miss deadlines for appeal and also created problems for families as they attempted to maintain current supports and services or qualify for new ones. Families were either not informed about, or did not understand the linking or de-linking of other benefits. For example, families consistently reported receiving misinformation or no information regarding their children's eligibility for Medicaid. Based on a denial of SSI benefits, parents reported being informed that their children no longer qualified for Medicaid. As a result, many parents stopped utilizing medical services and supports, when in fact, the 1997 Balanced Budget Act required states to restore Medicaid benefits for children who were removed from SSI due to changes in eligibility requirements. While this represented a huge victory for children and families in need of the benefit, the inability of the system to “get the message out” to families about the changes left many families without medical services and supports for their “eligible” children. This lack of information or misinformation had a negative impact on their ability to make informed decisions or plan for the future.

While there may be one person in each state (e.g., State Medicaid Director) that can answer all the questions about a legislative/policy change, that person probably is not directly available to the families. States and federal agencies must identify family support agencies where families seek information (e.g., schools, pediatrician offices, mental health centers, neighborhood service centers), and work to provide relevant information to the frontline workers who have direct contact with families. Local supports and services should be aware of where families are most likely to go for information and whom they ask for help (e.g., teacher, therapist, doctor, natural helper in the neighborhood) and, then, systematically equip them with the knowledge to be helpful.

⁵ Buck, J. (2001) *Medicaid and children's mental health services* Center for Mental Health Services, Substance Abuse and Mental Health Services Administration: Rockville, MD.

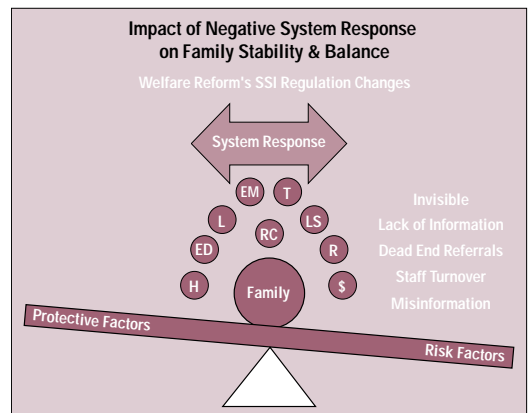
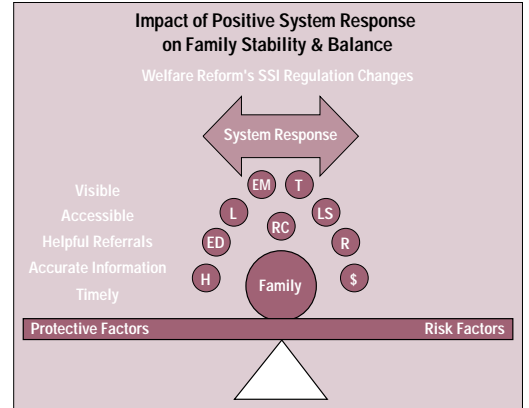
The response of a service and support program has an enormous impact on the balancing act that many families described, juggling issues of physical and emotional health, education, legal, employment, transportation, living situation, recreation, and finances. The study found that local agencies may respond in a manner that, when a legislative/policy change occurs, increases risk factors. Families in the study described these responses as: lack of information about the existence of an agency that can be helpful; an agency not having information or giving out wrong information; staff giving families referrals that were not helpful; or, agencies where they never spoke to the same person twice. The study also found that local agencies may respond in ways that increase the protective factors for families. These responses include: an agency's being visible; easy access to that agency and their information; accurate information and helpful referrals; and, providing information in a timely manner.

While federal, state and local entities work to improve ways of communicating legislative/policy changes to those most affected, the reality for families is that in order to obtain a comprehensive picture of all that the change may imply, they must often ask more than one person, in more than one agency. Families must gather as much information as possible, from accessible and reliable sources, in order to make informed decisions and plan for their future. While study team members received much of their information about the policy change from family and advocacy organizations such as the National Alliance for the Mentally Ill (NAMI), Bazelon Center for Mental Health and Law, or the Federation of Families for Children's Mental Health (FFCMH) or from internet sites such as the Government Accounting Office (GAO), the information provided by these entities did not reach most families, especially those not connected to a CMHS grant site.

● Importance of the policy change process

While the policy change for SSI occurred in August 1996, it took a number of years for many families to complete the process. The resulting impact on the children and families the legislation targeted will take even longer to fully understand.

The impact of the SSI policy change process was most evident when looking at the experiences of families with the appeal process. The appeal process places families in a difficult situation, being able to keep their benefits during the appeal, but putting themselves at risk of paying back their cash benefits should they lose their appeal. To reduce this dilemma, appeals need to be handled as quickly as possible. If appeals are decided in a timely manner, the financial consequences of allowing families to retain their money during the appeal process would be minimal.



KEY QUESTION: Is adequate support available to assure that families of all cultures receive assistance in applying for SSI and SSA officials understand the impact of different cultures on the applications and/or re-determination process?

ANSWER: No. While the SSI report did not look specifically at the impact of specific ethnic populations, the few families in the study with Spanish as their first language reported that they often did not receive materials in Spanish and did not have access to a bilingual person at the SSA office.

In 1999, 12.5% of all children 18 and under lacked health insurance; of the 9.6 million uninsured children, 6.8 million had incomes below 200% of poverty.

Sixteen percent of adults lacked health insurance.

Coupled with the loss of SSI, health care coverage for these families was sometimes non-existent.

Kenney, G., Dubay, L., & Haley, J. (2000)⁶

KEY QUESTION: How are the needs of families whose children have lost or cannot qualify for SSI being addressed? Is cash assistance available for these families? How are specific service needs—previously covered by the child’s SSI benefits—being met?

ANSWER: *During the time of the study, many families were still trying to sort out the “fall-out” of the changes in SSI. Many families sought support, financial and emotional, from informal resources, such as relatives, friends or religious institutions. By the end of the study, while few families had yet to seek support from formal service agencies to make up the loss of the SSI cash benefit, many had sought help from formal agencies throughout in providing continued health care coverage/Medicaid for their child and to obtain mental health services.*

● Importance of physical and behavioral health care coverage

Related findings consistently suggest the importance of physical and behavioral health care coverage, an especially critical benefit in families with children who have a serious behavioral or emotional disability. Many families viewed the loss of medical benefits as being more devastating than loss of income with most families reporting that the most important motivator for their (almost universal) decision to appeal was financial need in health care areas and their fear of losing Medicaid. For many families in the study, the primary caregiver and/or spouse lacked health insurance. These findings emphasize that coverage for behavioral health needs to be available to all families, most particularly poor families with children with emotional disabilities.

For state and federal policy makers, the relationship of the health benefit and income benefit must be thoroughly understood. For local supports and service providers, the relationship between these should also be clearly defined with the added understanding of the impact on the particular services and supports their agency offers. For these agencies, all frontline practitioners and those that may be in positions to answer questions, for example, the receptionist, must be able to clearly convey the information to the families they serve. And, for families, the relationship between health benefits and income benefits and the impact of changes on one to the other must be clearly understood.

● Importance of a basic minimum income for the well-being of children and families

The findings of this study suggest the importance of a basic minimum income to the well-being of families. For most families, the cash benefit plays a large role in total family income. Families reported that as a result of changes in their children’s SSI status, a portion of their household income was eliminated, creating many financial difficulties and changes in essential areas of living and “normalization” for their children. Families also reported the stress of the financial loss had an impact on family relationships, and on mental and physical health. The families in the study exist at or near poverty level.⁷ Feeling they will never “get ahead,” many families experienced one catastrophic situation after another. For example, loss of the

⁶ Kenney, G., Dubay, L., & Haley, J. (2000). Health insurance, access, and health status of children. In *Snapshots of America’s families II: Findings from the national survey of America’s families*. Washington, D.C.: Urban Institute.

⁷ According to M. Harper and S. Vandivere (1999) in “Poverty, Welfare and Children: A Summary of the Data,” *Child Trends Research Brief*, growing-up at or near the poverty line (\$16, 660.00 for a family of four in 1998) can affect the quality of a families housing, children’s access to nutritious food and adequate health care, and parents ability to provide toys, books, and recreational or educational opportunities for their children.

SSI benefit contributed to the loss of a car for one family. Consequently, meeting family transportation needs became complex; while one parent needed to get to work, the other was concerned about meeting their child's medical needs, and getting to the school when they called about the child's behavior problems.

- **Importance of the family as a complex system within a system**

Joan Patterson wrote about the effects on the whole family when a child is diagnosed with a chronic condition. She called this *circular or reciprocal effects*, emphasizing the importance of thinking systemically when studying children and their families. One basic assumption of systems theory is that a change in one part of the system (i.e., the child) leads to changes in other parts of the system (i.e., the family).⁸

The SSI Family Impact Study identifies a *cascade effect*. As illustrated in John's story (John Loses SSI Benefit on page 41), the loss of income as a result of a policy change in one area of support had a comprehensive, and as described by John's father, "downward spiraling effect". The loss of income for a family with a child who has a mental illness is complicated and comprehensive in effect, especially with the complex array of services a family may have for support. The decisions and choices these families face are equally complex and the effect of those choices can be the difference between providing health care for one child, or a roof over the family's head. While it is difficult to identify the cause and effect in John's story, as well as many other families' stories, they aptly illustrate an important sequence of events.

- **Importance that the primary caregiver was most often the sole provider of daily care for the child**

Most families in the study consisted of children with a single mother. While the supports were important, families reported that it was critical that the primary caregiver remain in the home to care for the child with the disability. Primary caregivers, most often the sole provider of daily care for the child, realized that without the money from SSI, they would have to seek employment, thereby seriously reducing the amount of time they could spend with their children, leading to issues around continuity of care.

⁸ Patterson, J. (1996). Family research methods issues and strategies. In Heflinger, C.A. and Nixon, C.T. (Eds.) *Families and the Mental Health System for Children and Adolescents*, (pp. 117-144). Sage Publications, Inc., Thousand Oaks, CA.

KEY QUESTION: Are families expressing concern that without SSI benefits, they will no longer be able to raise children with mental health or behavioral problems at home?

ANSWER: Yes. A few families did express feelings that they would have to have their child move out of their house as a result of the loss of SSI. While this did not happen broadly, one child was removed to foster care. The mother reported that the loss of SSI was connected to her daughter being placed in foster care. Not being able to care for their children with special needs was also expressed by the many single mothers in the study, who were feeling pressured to return to work or increase their work hours. Families made heroic efforts to keep their children at home.

● Importance of the families' strong commitment to keeping their children at home

Most of the families in the study did not lose their children to out-of-home placement—not because the system “made up for” the loss of SSI and wrapped other supports around them—but because these families exhibited enormous resilience and commitment to their children.

While some families expressed guilt and shame about their inability to provide for the needs of their children without public assistance, one of their most vocal fears was attack on their suitability as parents, possible prosecution for negligence and, ultimately, losing custody of their children. This study found families making heroic efforts to keep their children at home.

There is no question that the loss of SSI had the effect of stimulating the resourcefulness of some of the families as they sought to identify other sources of income, to find assistance for their children, and to successfully challenge the system. In this regard, there were some benefits to losing the SSI benefit for some of the families. However, these benefits overall were not without enormous cost in added stress, diminished quality of life, and loss of critical supports. Policy has to strike a balance between relying on the strengths of families, and providing families with the basic supports they need to do well. Families in this study would maintain, with considerable justification, that the SSI policy changes did not strike this balance. The changes relied too heavily on the families' ability to come up with resources to replace basic critical supports.

● Importance of informal supports

Our findings suggest the importance of informal, natural supports and services. Although families wanted practical information, they found few formal supports for assistance in the SSI review or appeal process. However, tangible support in meeting basic living needs and emotional/spiritual support was viewed as very important with most of this help coming from informal sources.

In the study, families in Kansas not only reported the most frequent use of formal and informal supports, but also more readily identified positive outcomes, regardless of the disposition of their review and appeal(s). New York and Florida families found it difficult to identify positive outcomes related to the legislated review of their child's eligibility for SSI. Families that had access to more supports, both formal and informal, reported feeling more hopeful about the future.

There are two major policy implications related to this finding. First, when eligibility criteria are being changed or benefits are being eliminated, policy makers can help identify and shore up natural systems of support. Secondly,

policymakers also must understand the fragility of natural social support networks and recognize that informal support networks cannot take the place of necessary formal services.

● Importance of strategic interventions

A goal of the study was to look at how people make real-world decisions. This information can help identify the specific criteria used by individuals experiencing a policy change enabling policymakers and frontline practitioners intervene at different points in the decision-making process to make things better for families. For example, an impact on mental health frontline practitioners might be the ability to anticipate the needs of families as they experience a policy change. As illustrated in John's Loss of SSI Benefits, a case manager may anticipate a need for sibling counseling, or alternative housing or budget plans, and help to identify a need for critical informal and formal supports. Identifying strategic areas of support and intervention might help mitigate the negative effects on families. While across families' stories, a relatively consistent picture of families experiencing the effects of the SSI changes emerges, the individual experience of each family creates opportunity for service providers to intervene strategically.