



# SECTION 2

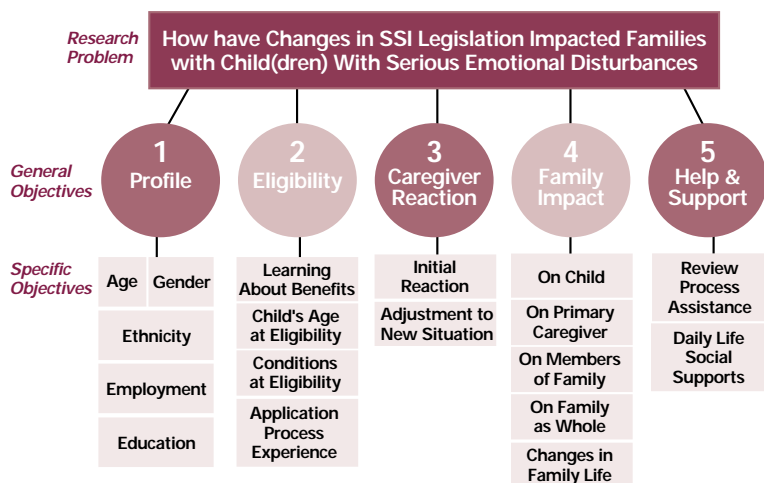
## METHODOLOGY

# METHODOLOGY

## Design

In order to deepen understanding of the impact changes in the SSI regulations had on children and families, the SSI Family Impact Study utilized a qualitative, multi-site, longitudinal approach. The study method was designed to examine the short-term effects of the new regulations, as well as effects over time. It is a thorough and systematic method to describe what happens to families, and helps to provide an understanding of the subtleties and complexities of the families' experiences. The SSI Impact Study complements more quantitatively designed studies through its in-depth focus on a limited sample of families, which adds a "human face" to other studies examining the impact of this legislation.

*"The interpretive explanation of qualitative analysis does not yield knowledge in the same sense as quantitative explanation. The emphasis is on illumination, understanding, and extrapolation rather than causal determination, prediction, and generalization" (Walcott, H. 1994).<sup>1</sup>*

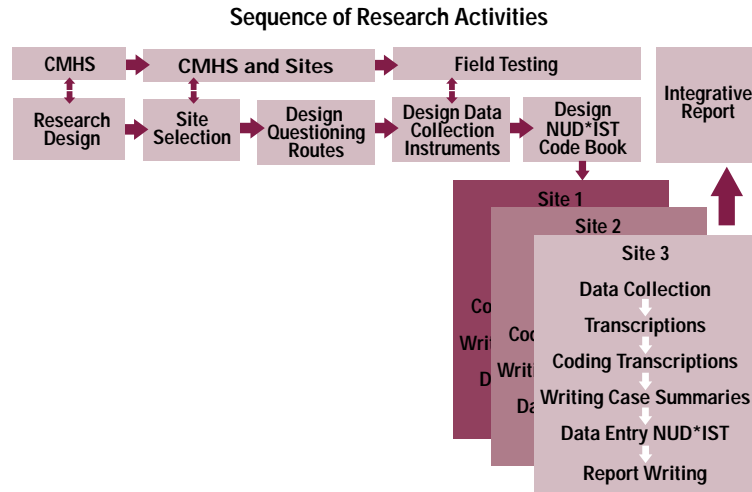


*The figure at left provides the details of the study purpose and objectives and delineates a linkage between the purpose, objectives, and the specific questions developed for the protocol (Appendix A).*

The study utilizes a form of case study methodology that derives its findings from interviews conducted over time, with multiple sources, including the primary caregivers and other individuals identified as providing support to families. This process begins with initial in-depth, in-person interviews which are followed up with telephone interviews every three months with the primary caregiver. The purpose of the prospective, longitudinal design of the interview was to gather information on changes in the family's status during this period, with special focus on decisions that the family made in response to their situation, and how these decisions affected them. For example, families considered decisions such as to continue or discontinue particular services, to increase or decrease employment, to appeal or not to appeal the re-determination decision, or to change residence or household arrangements.

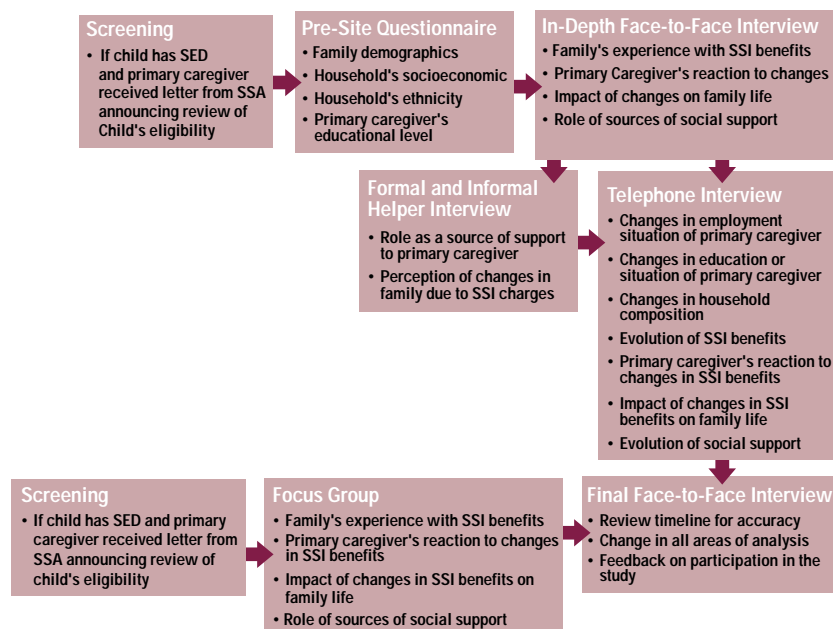
<sup>1</sup> Walcott, H. (1994). *Transforming qualitative data: Description, analysis, and interpretation*. Thousand Oaks, CA: Sage Publications.

Research activities were conducted by a multi-disciplinary research team comprised of researchers, parents, and ad hoc parent/team members from individual sites.



In addition, the study utilized a series of focus groups with parents to enhance the understanding of how families have been impacted by the legislative changes. Focus groups of parents whose children were receiving SSI benefits because of a serious emotional disturbance were conducted as part of the study for three purposes. First, this method involves bringing together individuals with common characteristics and therefore often provides unique and rich data as individuals have a chance to think through their situation and their views in the context of a guided and focused discussion in which they are also hearing the views and experiences of others. Second, the information gathered through this means can be compared to the information gathered through in-depth interviews and longitudinal data collection procedures. Third, the use of focus groups offered an opportunity to economically secure information about the views, experiences, and insights of a larger and more diverse group of parents and other caretakers.

### Data Collection Instruments



Data collection tools utilized throughout the study were first pilot tested by the study team with families who were also experiencing the legislated SSI review. As a result of many revisions, the study team was confident that the final interview protocol was culturally sensitive and would comprehensively capture the families' experience as it related to the changes in the SSI eligibility and review process.

Criteria for participation in the study was based on the families' receipt of a letter from the Social Security Administration (SSA) giving notice that their children's eligibility for SSI benefits was slated for reevaluation. It was also based on self-reported information that their children were receiving SSI benefits for a serious emotional disability. Families from three communities self-selected through a variety of recruitment efforts such as fliers in the schools, and at mental health centers, and presentation of the study objectives and needs at family advocacy meetings. Forty families, between 12 to 15 from each of three sites, were selected to participate in the study. The sites included areas in Kansas, Florida, and New York. During the study, one of the three participating sites had families who were served by the federally funded Community Mental Health Services Program for Children and Families (KanFocus in Kansas). A few New York families were

### A Family Over Time

	May 1998	Sep 1998	Nov 1998	Feb 1999	June 1999	Dec 1999	Feb 2000
<b>BENEFIT STATUS</b>	SSI denied under appeal, continues receiving check	Waiting for new court date for appeal review	Waiting to reschedule	Still waiting; afraid to check status	Still waiting for word, but believes she has won due to bank deposit	Results of appeal positive less payment	Received letter of eligibility
<b>CHILD</b>	Diagnosis of ADHD & OCD SED Classroom		Behavior worsens, transferred to SED Center	Behavior deteriorated; 4 days in crisis center	Week in crisis center; diagnosed with Tourette Syndrome	Son's behavior improves, new SED Center placement	Doctor thinks son has seizures and needs neurological testing
<b>MEDICAID &amp; HEALTH COVERAGE</b>	Unclear medical status, pays for prescriptions	No medical coverage; Father required to provide coverage	Father provides 1 month insurance coverage; drops policy; mother afraid to inquire	Learns medical coverage is active, pays for crisis stay		Does not use Medicaid Pays out of pocket to retain son's doctor; uses Medicaid for therapist	
<b>LIVING ARRANGEMENTS</b>	One-bedroom Apartment		Child reported to sleep on couch, family unable to relocate	Family evicted, moves to 2 bedroom house w/income tax refund	Mother reports son has new bed, no longer sleeps with her		
<b>INFORMAL SUPPORT</b>	Father lives in Europe	Father not reliable, mother's girlfriend supportive	Girlfriend helps babysitting when available	Father moves to WA, paternal aunt (NJ) met this year offers support	New boyfriend helps buy new bed; father no longer sends \$	No support from friends or family	
<b>FORMAL SUPPORTS</b>	Does not seek services due to fear; Misses hearing due to work				Fear of losing child due to sleeping arrangement prevented request for services		
<b>HEROIC EFFORTS</b>	Pays rent ahead; Frequent dental care for son				Mother sick, but uses money to move rather than go to doctor		
<b>INCOME</b>	\$800/mo. Earnings \$300/mo. SSI Rent=\$380		Earnings based on piecework, production down and pay suffers		Ex ordered to pay \$75/mon earns \$5.50/hour + bonus SSI/month = \$380 Rent = \$500	Received only 3 child support checks \$800/month earnings \$253/month SSI Rent = \$500	\$160-250/mon SSI depending on earnings \$800/mon Earnings \$75/mon child support (irregular)

*Timelines were created during the data collection process to review, over time, the experiences of the families (see Appendix C). It was updated and revised if necessary, after each interview by the study team member and then reviewed for accuracy with the family member during the final interview. The timeline for the family represented above looks at 8 of the 21 areas of analysis.*

### The SSI Family Study looked at 21 areas of analysis

- Benefit Status
- Reaction to Review
- Experience with SSA
- Experience with SSI review and appeal process
- Use of SSI Money
- Impact on Family
- Impact on Children
- Positive Impact
- Sources of Income
- Household Employment
- Family Composition/Living Situation
- Child Diagnosis/Behavior
- Primary Caregiver Education
- Child Education
- Primary Caregiver
- Other Family Member Health
- Child Health
- Decision-Making
- Support
- Co-occurring Events
- Impact on Medicaid or Other Health Insurance

connected to a CMHS site, F.R.I.E.N.D.S., while Florida did not have a CMHS site.<sup>2</sup> Through this selection process, it was possible to examine the degree to which there are different effects of the change in SSI regulations in communities participating in the federal program and those that were not.

Initial interviews were conducted between February and June of 1998. Based on the longitudinal design, all families were first interviewed in-depth and in-person, and then re-contacted every three months by telephone. The last in-person interviews were conducted during the final phase of the study between February and June of 2000. Focus groups were conducted in the Florida and New York sites at two data collection points, the beginning and the end. In Kansas, the focus group was conducted at the beginning of the study only. The family member interviewed was paid for each phase of their participation in the study, 25 dollars for the initial and end in-person interview and 10 dollars for each telephone interview. Focus group participants were paid 20 dollars.

## Analysis Plan

The study analysis was completed using a data transformation approach. Data transformation is an analysis process that allows for the representation of the point of view of interviewees through a systematic procedure. Information is transformed, step by step, from raw data into interpretive descriptions. The process controls the level of interpretation, follows a traceable pattern and increases the level of reliability of the qualitative data.

In the description phase of the study, the families' experience was described by extracting themes from the transcribed interviews. Themes were extracted within the context of each study category and each of the seven data collection waves. Each identified theme was accompanied by a corresponding quotation, believed by the researcher to best reflect the theme. Once the themes were listed, the analyst, working inductively, then looked for emergent patterns in the data within each wave. With the goal to present the families stories as accurately as possible, the analyst moved back and forth between the extracted themes and the actual data in search for meaningful patterns.<sup>3</sup>

The findings from this data collection were analyzed by a variety of methods, including the use of the QSR-4 NUD\*IST<sup>4</sup> computer software. Interviews were audio taped, transcribed, and then imported into NUD\*IST and categorized following a coding list based on the study's research questions. The research team summarized the findings and identified points of convergence and divergence. In addition, weekly meetings with the research team allowed the continued emergence of issues and themes.

<sup>2</sup> The CMHS Children and Families Program is funded through the Center for Mental Health Services. Its primary objective is to help states demonstrate and promote more effective ways to organize, coordinate, and deliver mental health services and supports for their increasing number of children and families who need help from more than one service system. During the final phase of the study, Hillsborough County, Florida also became a CMHS funded site. New York's CMHS funded site, F.R.I.E.N.D.S., helped recruitment efforts, however most families participating in the study were not in the F.R.I.E.N.D.S. service area and thus were not connected to the site.

<sup>3</sup> Walcott, H. (1994). *Transforming qualitative data: Description, analysis, and interpretation*. Thousand Oaks, CA: Sage Publications.

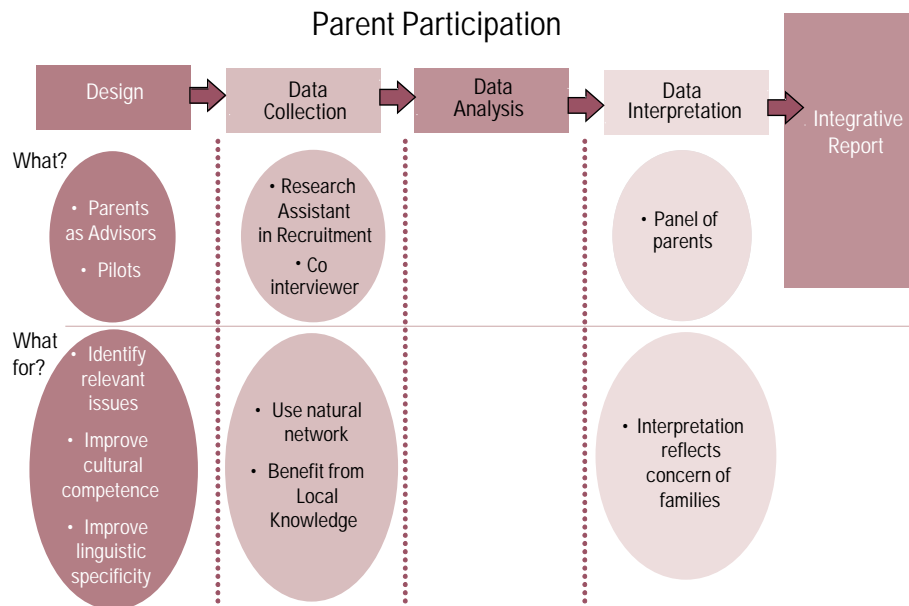
<sup>4</sup> QSR-4 NUD\*IST [computer software]. (1997). Melbourne, Australia: Qualitative Solutions and Research Pty Ltd.



This report uses two different types of data to describe the families who participated in the SSI Family Impact Study. The first type, presented in the Description of Families Section, offers aggregate demographic data for the entire research sample based on information collected from the primary caregivers at the point of the first face-to-face, in-depth interview and follow-up interviews. The second type, described in the Key Findings Section, relies primarily on data obtained through the in-depth interviews and focus group discussions with a small number of primary caregivers in each of the three sites which are more qualitative descriptors of who they are and the context in which they live and raise their families.

## Building a Research Team

Careful attention was paid to the construction of the study's multi-disciplinary, diverse research team. Throughout the course of the study, disciplines represented on the team included: a social worker; a pastor; a special educator; two to three parents of children with a serious emotional or behavioral disorder and experiencing an SSI review for their children; a therapist; a front line worker; a linguist; and, qualitative research and analysis experts. Two additional parents from each site were hired as part of the research team conducting interviews and recruiting parents in their locales.



*Parents were hired as primary researchers in the study and were involved in multiple phases of the study including study design, protocol and instrument development, participant recruitment, data collection, data interpretation, and dissemination.*

While there are identified challenges to family/community partnerships in research and data collection, such as pressure on family/community research assistants, trust barriers, and coordination of study without a local base of operation, the benefits are many. These included more detailed and expansive family responses, family voices being heard, expanded knowledge of effects of the changes on families, and use of research findings by family advocacy organizations.

The research team was also ethnically and racially diverse with trilingual capacity in English, Spanish and Creole and included Native American Indian, African American, Latino, Anglo, and Asian/Pacific Islander heritages.

## Recruitment and Retention

Participant recruitment efforts for the study posed many challenges. First, the eligibility criteria to participate was very narrow and no central listing of eligible population members was available to the study team. Eligibility criteria included:

- 1) the child had to have been diagnosed with an emotional or behavioral disorder;
- 2) the child had to have undergone an eligibility review prompted by the SSI changes; and,
- 3) the child had to have either lost or was at risk of losing benefits.

And finally, because the population was multilingual (some participants were Spanish speakers only) and from three different states (Florida, Kansas, and New York), recruitment challenges included matching language resources, logistical considerations and financial restraints.

To address these challenges, recruitment strategies were multi-faceted and focused on enhancing retention. They included:

- 1) personalizing all correspondence, flyers, and contacts to encourage building of long-term relationships;
- 2) obtaining names of collateral contacts for all recruited participants;
- 3) enlisting assistance of parent groups and residents of targeted neighborhoods as recruiters;
- 4) using word of mouth advertising...played “who do you know?”;
- 5) using “broadcast” e-mail within host grant agency;
- 6) posting flyers in places with high traffic of service providers and clients such as: legal aid offices, restrooms, mental health agency waiting rooms, social security offices, food stamp offices; and, made presentations at staff meetings of service providers.
- 7) assembling a team of recruiters who were bilingual;
- 8) hiring parent research team members;
- 9) translating all flyers and correspondence in Spanish and English; and
- 10) programming a 1-800 phone with part of the outgoing message in Spanish directing them to a phone answered by a Spanish speaking recruiter.

One member of the research team coordinated the recruitment efforts utilizing a variety of recruitment methods. One highly effective method was to piggyback on an in-house project from another department within the de la Parte Florida Mental Health Institute that had done a general solicitation of families interested in participating in research projects in the area. Recruitment activities also utilized the existing Center for Mental Health Services sites' mental health network structure with a parent advocate serving as the point person for recruitment. This occurred in the study sites in Kansas and New York. In these sites, parent advocates who were residents within targeted neighborhoods were employed as recruiters. In Florida, mental health and health administrators and advocates at the state level recruited potential study participants through their existing networks.