



SECTION 7

FUTURE DIRECTIONS

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This report presents an analysis of a prospective, longitudinal study designed to collect qualitative data over a two-year period with 40 primary caregivers participating in in-depth interviews and 30 primary caregivers participating in focus groups in specific areas of three states: Kansas, New York and Florida. This report is comprehensive but not exhaustive in its coverage of the impact of the changes in regulations and eligibility of SSI benefits on families whose children have an emotional or behavioral disability.

While the SSI study accomplishes multiple tasks by providing an extensive description of a sample of families, many other areas emerge to be addressed through future research. The field needs to further investigate:

- *The experience of children and families utilizing public assistance services as a child transitions from children's services to adult services and supports.* These young adults are more vulnerable to experience interruptions in care. While transitions are difficult for most, for children and youth with emotional or behavioral challenges, and families with complex support from public assistance services, the transitions are often much more difficult.
- *The vulnerability of families experiencing prolonged conditions of financial stress and poverty and their susceptibility to personal degradation.* Many of the families participating in this study experienced not only managing the obvious, tangible consequences of poverty, but also reported dealing with negative attitudes and often unpleasant and rude manners of individuals providing professional “services” and “supports.” Issues of self esteem and self confidence emerged.
- *The important role that informal supports play and whether on-going support allows families to be more resilient in facing continuing change and uncertainty.* We need to better understand where families go for help. It appears from the study that families who had access to more support—both formal and informal—reported feeling more hopeful about the future. While the study did not specifically examine this, one can speculate that feeling more hopeful may have affected outcomes for these children.
- *The impact of the loss of SSI benefits on earnings income and the cost of resulting hospitalizations, home repairs as a result of destruction of property, etc. from increased negative behavior of the child.*
- *The extent to which health care reform activities have impacted these families.* Further study is needed to determine the extent to which any health care reform activities taking place in the participating sites had an impact on the experience of these families during the SSI policy change. Studies,

When one participant was asked what it has been like for her to take part in the SSI Family Impact Study, she replied, "I don't think about it that way, because you're so nice. I feel like we're just talking about stuff. I was telling the girls at work today that you were coming over, and they're like, 'what does she do?', I said 'nothing.' We just sit there and talk for about an hour. I don't feel like we're doing a study or doing a form. It's like we're just talking, shooting the breeze."

such as the Health Care Reform Tracking Project, have shed some light on the impact of health care reform activities on families who have children with serious emotional disorders in general.¹

- *The advisability of a policy wherein even if children do not qualify for disability payments they may qualify for Medicaid.*
- *The impact of the loss of SSI benefits and the impact of the legislative change process on diverse racial and ethnic groups.* Also, further examination on the impact of these changes on new immigrant families and long-term non-citizens is needed. While this study did not address non-citizens, the legislative ride for these families was bumpy, with numerous deadlines and changes in eligibility.

The SSI Family Impact Study demonstrates the need for timely, longitudinal, and qualitative research, not only because of the long process nature of legislative policy changes such as SSI, but also because the impact of these changes for families may unfold over a long period of time. For example, many families expressed concern that not today, but some day, they might have to place their child in foster care or with a relative. The Family Over Time chronological timeline on page 11, illustrates the importance of longitudinal research when looking at the impact of policy change. From this story, as with most of the experiences shared by families participating in the study, we can see the final outcome of the SSI appeal only towards the end of the study. We are able to see the on-going and varied needs of the child and the variability in the child's behavior. Utilizing a qualitative approach, we eventually understand the reason for the child not using Medicaid although eligible. We come to understand the reasons for the variable use and availability of both formal and informal supports. The timeline provided a more complete picture of the complexities of the family's experience and the non-static nature of the phenomenon being studied.

It has become too common to place blame on parents for their children's problems, or place blame on children for their parent's difficulties. An in-depth, comprehensive picture is critical when we see poor families, or families experiencing constant instability, criticized for being poor decision-makers. The effects of their total experience, added to the system's ineffectiveness for providing accurate information, sets the family up to fail. Families need to be able to make decisions from a position of strength and to be viewed and evaluated in that light. Operating from a system's perspective, a longitudinal study can eliminate blame and be more respectful of children and families participating in research.²

¹ Pires, S. A., Stroul, B. A., Armstrong, M. I., (2000). *Health care tracking reform project: Tracking state health care reforms as they affect children and adolescents with behavioral health disorders and their families –1999 Impact Analysis*. Tampa, FL: Research and Training Center for Children's Mental Health, Department of Child and Family Studies, Louis de la Parte Florida Mental Health Institute, University of South Florida.

² 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.

What is evident in this study is that, behind most of the children, are one or more parents struggling to keep up their sense of hope, and their emotional and physical energy, and searching for solutions to the needs of their children. Most families made adaptations to the loss of SSI benefits and to other changes resulting from the new legislation *only* with heroic efforts and with consistently high levels of stress. The family voices contributing to the SSI Family Impact Study expressed their experience of the changes of SSI, not as an ultimate outcome issue, but as a quality of life issue. This qualitative shift in examining the impact of external intervention on the lives of children and families, whether in policy or mental health and substance abuse treatment, is the challenge and responsibility of evaluators.