

Chapter Three

The Commission's Deliberations

Introduction

Congress usually creates commissions to help resolve difficult policy issues, making their work both challenging and controversial. Even by this standard, the circumstances that confronted the National Commission on Childhood Disability were unusual. In the four months between the August 1994 enactment of Public Law 103-296, which established the Commission, and Secretary Shalala's appointment of its members in January 1995, control of both houses of Congress shifted from the Democratic to the Republican party. The resulting change in political agenda was most marked in the House of Representatives, where the election campaigns of Republican challengers had centered on the Contract with America. This ten-point program called for reducing the federal deficit and narrowing the scope of federal government activities. One of its major targets was the welfare system, which the Contract promised to return to the control of the states. President Clinton had also sent Congress a welfare reform proposal, setting the stage for national debate. The new House leadership pledged that the body would vote on all ten legislative initiatives in the Contract within 100 days, by mid-April. By statute, the Commission's report was not due until November 1995.

House Action

In mid-January as the Commission began its work, the Subcommittee on Human Resources of the House Committee on Ways and Means began hearings on welfare reform, defined by the House leadership to include the SSI program. Within two weeks of the Commission's first meeting, the Subcommittee approved a welfare reform bill that reduced the number of children receiving SSI by approximately one-third and cut projected SSI program outlays to children by \$12.1 billion over five years. This legislation, unnumbered at the time of its approval by the Subcommittee, subsequently became H.R. 4, the Personal Responsibility Act of 1995. The Commission's first meeting was February 3. The Subcommittee approved welfare reform legislation on February 15. Revisions of the bill prior to full Committee consideration reduced the savings from \$12.1 billion to \$10.9 billion. The bill achieved these savings in two ways.

First, it eliminated the Individualized Functional Assessment that SSA established in response to the *Zebley* Supreme Court decision.¹ The pragmatic effect of this change would be to increase the stringency of SSA's eligibility criteria for allowances based on impaired functioning, since the agency's only other functional test, the "functional equals" step, has

¹ The bill accomplished this by eliminating the "comparability standard" for children in the SSI statute. See chapter two for a complete discussion of the *Zebley* decision.

more stringent criteria.² Second, the bill prohibited the payment of cash benefits to nearly two-thirds of the remaining children -- those who are not institutionalized or at immediate risk of institutionalization.³ No longer eligible for cash, these children could apply for services under new state block grants established by the bill. The proposed block grants would provide the states with funding equal to 75 percent of the SSI benefits that would have been paid to eligible children under current law. The bill imposed no requirements for the provision of specific services by states nor for the receipt of specific services by eligible children.

The legislation was placed on a fast track for consideration by the full Committee on Ways and Means, with the goal of securing approval of the full House within the leadership's 100-day deadline. By late March, it was approved as H.R. 4 by both the Committee and the House. This accelerated pace meant that the House was unable to consider the Commission's recommendations before acting on the SSI provisions of the bill.

The Commission

While the House action gave Commission members reason to accelerate the pace of their work, doing so was problematic for several reasons. First, the charge at the core of the Commission's mandate -- to examine alternative definitions of childhood disability for the SSI program -- was a fundamentally technical one and not likely to yield to rapid analysis. A second obstacle was the generally sketchy understanding of the children who receive SSI today: the nature and extent of their disabilities, their current utilization of medical services, their need for and use of other disability-related goods and services, and their actual use of SSI funds. The Commission found little systematic data or analysis to shed light on these issues.

Third, as currently structured, the SSI program for children does not distinguish between their needs as low-income children and their needs as children with disabilities. As children from low-income families, their needs for food, shelter, and clothing are much like those of other such children. Yet as children with disabilities, their needs are highly diverse and often include modified forms of basic necessities, such as specialized food and clothing and home modifications. Given this diversity, a careful examination of children's need for SSI requires looking beyond the program itself to determine the adequacy of other services and benefits. HHS Secretary Shalala acknowledged this complexity and stressed the interaction of SSI with other federal and state programs. The Secretary urged the

² For a comparison of eligibility determination under "functional equals" and the IFA, see chapter one.

³ Here the criterion was whether the child would have to be institutionalized but for the personal care provided by a parent or caregiver.

Commission to conduct a broad, cross-cutting analysis of the children's needs rather than "limit its study to the causes and consequences of [the program's] growth."⁴

Despite the clear difficulties in expediting its work, the Commission decided that its first responsibility was to inform Congressional consideration that was already under way. Anticipating Senate action on welfare reform in early July, the Commission initiated a series of bi-weekly meetings. It declined to undertake new research projects to address its Congressional charge, opting instead for a comprehensive review of existing knowledge of the SSI program and the children it serves. To fill the numerous information gaps, the Commission consulted with medical and other professionals, families, educators, and other close observers of children with disabilities.

The Commission established three task forces to work on specific issues. One group analyzed options for revising the SSI definition of disability. A second considered the role that private organizations could play in improving SSA's service delivery. A third examined growth in the SSI program and the potential universe of eligible children.

In this way, the Commission collected and synthesized information from a wide range of sources. The most important of these were:

Specialists in childhood disabilities. The Commission sought expert testimony from specialists in childhood mental retardation, Attention Deficit Hyperactivity Disorder, behavioral and emotional impairments, and neurogenetics. It heard from specialists working in university research programs (including Duke, Johns Hopkins, and Vanderbilt Universities), and from representatives of professional organizations, including the American Academy of Pediatrics, the National Center for Learning Disabilities, and the National Association of School Psychologists.

SSI administrators. The Commission had extensive conversations with SSA staff responsible for the design of the medical listings for children and for the IFA; with agency staff involved in SSI outreach; with state DDS personnel, including psychologists, physicians, disability examiners, and staff liaisons with the public school system; and with representatives of the National Association of Disability Examiners.

Families. At public hearings in Washington, D.C., Baltimore, and Philadelphia, the Commission heard from 45 families -- primarily parents of children with disabilities -- who discussed their experiences. It also received testimony from representatives of family organizations, including Family Voices, the Federation of Families for Children's Mental

⁴ February 3, 1995, Commission transcript, pages 138-9.

Health, the National Parent Network on Disabilities, and Children and Adults with Attention Deficit Disorders.

SSI regulations and program instructions. The Commission reviewed SSI regulations implementing the 1990 *Zebley* decision and the 1990 revision of medical listings of childhood mental impairments; a series of instructions to the DDSs aimed at tightening adjudications; training materials for adjudicators; and agency instructions to physicians, nurses, social workers, and school personnel on providing medical evidence.

Individualized Functional Assessments. The Commission analyzed a sample of IFAs completed by state disability determination service (DDS) staff for 51 children who were approved for SSI disability benefits based on an IFA. The IFAs were altered to omit the children's identities.

Advocacy groups. The Commission met with representatives of major advocacy groups, reviewing with them their beliefs and experiences. These included national and local representatives of The Arc, United Cerebral Palsy, Community Legal Services of Chicago and Philadelphia, the Bazelon Center for Mental Health Law, and the Children's Defense Fund.

Program critics. The Commission met with many individuals who expressed concern about SSI childhood eligibility criteria, including DDS administrators, staff physicians, and a former staff psychologist; public school personnel; and Members of Congress.

Studies by government agencies. Commission members studied SSA's annual statistical profiles of children receiving SSI, as well as its audit of benefit allowances to children with emotional and behavioral impairments. They reviewed studies by the HHS Inspector General of SSI benefit allowances to children with mental impairments, Medicaid utilization by children with certain mental impairments, and the concerns of DDS program administrators about the IFA. The Commission also took notice of a General Accounting Office analysis of growth in the childhood disability program and its study of problems with the implementation of the IFA.⁵

Non-government studies. The Commission looked closely at the work of the National Academy of Social Insurance: its analyses of SSA's disability determination process, its profiles of families receiving SSI, and a study of services available to children with disabilities in Connecticut and Virginia. It also reviewed the 1995 Urban Institute study of federal programs for children with disabilities and an analysis by Mathematica Research, Inc., of a 1979 survey of parents of children receiving SSI. Further, the Commission reviewed a

⁵ See Appendix 4-D for a full listing of reviewed reports.

Human Services Research Institute survey which focused on the needs of children with disabilities and their families' use of SSI benefits.

Experts on other benefit programs. The Commission explored the concept of tiered benefits with a representative of the Department of Veterans' Affairs, which adjusts benefits to reflect the extent of impairment. It learned about disability benefits for children under European social insurance systems from an SSA specialist. It also received testimony from representatives of the Health Care Financing Administration (HCFA) who specialize in Medicaid coverage for children with disabilities, and with representatives of the Department of Education who specialize in the use of the Individualized Educational Plan (IEP) and Individualized Family Services Plan (IFSP) in Special Education programs.

A complete list of the Commission's sources appears in Appendix 3.

Several themes marked the Commission's discussions and analysis. All Commission members expressed the belief that the federal government can and should play a strong role in supporting children with disabilities and their families. Many members also expressed a concern that SSI be structured to motivate, not deter, parents in encouraging their children to accomplish all that they can. In addition, reflecting on their discussions with families, members expressed renewed recognition of the challenges and demands of raising a child with a severe disability and the importance of structuring government support to empower parents in this effort. The Commission's hearings showed great diversity in children's needs, suggesting the importance of a flexible form of government support. Finally, members expressed interest in formulating proposals to bring greater accountability to the SSI program.

Late in April, external events again influenced the Commission's deliberations. The Commission received a letter from Senator Bob Packwood, who was then Chairman of the Senate Committee on Finance, stating that consideration of welfare reform by that Committee was imminent.⁶ Chairman Packwood urged the Commission to accelerate its deliberations and asked for preliminary recommendations.

At that time, the Commission had a list of policy options under consideration. At its April 21 Baltimore meeting, the Commission responded to Chairman Packwood's request by reviewing these options and reaching agreement on a set of preliminary recommendations. (See Appendix 5.) Chairman Slattery provided these to the Senate Committee on Finance and the House Committee on Ways and Means, stressing that they were subject to revision.

During May, the Commission refined and expanded its preliminary recommendations. The most significant expansion was the addition of an alternative definition of disability for children for use in determining eligibility for SSI. This second position emerged when the

⁶ Letter from Senator Bob Packwood to Jim Slattery, April 20, 1995.

Commission split on a tie vote (seven to seven) during reconsideration of its preliminary recommendations. Unable to resolve this disagreement, the Commission included both options in its recommendations, along with the names of the members who supported each (see chapter four). Bills that embodied both of these options were introduced by members of the Senate Committee on Finance.

On May 24, 1995, Chairman Slattery shared a draft of the Commission's final recommendations with all the members of the House Committee on Ways and Means and of the Senate Committee on Finance. Since the Committee on Finance had moved more slowly to consider welfare reform than its Chairman had anticipated, the Commission was able to present its final recommendations to the Committee several days before it considered welfare reform.

Paralleling the division within the Commission, the Senate Committee on Finance was equally divided on the extent to which SSI childhood eligibility criteria should be tightened. Ten Senators supported a tighter standard offered by Chairman Packwood which was similar to the Commission's option I, while the remaining ten Senators supported a less stringent tightening of eligibility proposed by Senator Kent Conrad, which was similar to the Commission's option II.⁷ Chairman Packwood prevailed on the tie vote, and Senator Conrad's amendment was defeated. Senator Packwood's proposed eligibility criteria were subsequently included in a welfare reform bill sponsored by Senate Majority Leader Robert Dole and, in September 1995, was approved by the full Senate as part of that legislation.⁸

In July, the Commission formed a task force to propose a research agenda to address the informational gaps that had impeded its efforts. The agenda stresses the need to better understand the nature and extent of children's disabilities; the economic, social, and psychological impact of disability on families; the goods and services that children and families use; the extent to which education, technology, and treatment may improve children's long-term outcomes; and the evolution of childhood disabilities over time. The details of this agenda constitute the final chapter of the report.

⁷ These options are presented in the Executive Summary and in chapter four.

⁸ Senator Packwood's provision underwent minor modifications prior to its inclusion in Senator Dole's bill, but these did not alter the pragmatic impact of the proposed eligibility criteria. The Social Security Administration and the Congressional Budget Office interpreted both these provisions as requiring children to demonstrate "marked" limitations in two functional domains, as under the Commission's option I.