

Chapter Seven

Research for Future Policy Directions

Introduction

The following pages provide a blueprint for future consideration of support for children with disabilities and their families. This blueprint is needed because large gaps exist in the current understanding of childhood disability. These gaps severely impeded the Commission's deliberations and, until addressed, will continue to serve as a barrier to policy making. The needed investigation should focus on the following questions:

1. Who are children with disabilities in terms of their clinical, functional, and family status; their status over time; their relationship to the broader population of children without disabilities; and their relationship to the narrower population of children with disabilities who receive SSI?
2. What interventions are helpful (and harmful) in improving outcomes for children with disabilities and their families? What outcomes are achievable for children with disabilities?
3. Does the form in which support is provided (cash, direct services, or vouchers) influence outcomes for children with disabilities and their families and, if so, how?
4. What outcomes should public support for children with disabilities aim to achieve?¹

In recommending research on these topics, the Commission wishes to stress several points. First, childhood disability is a complex phenomenon, not only medically but also in social, psychological, economic, and educational terms. Given this complexity, the questions posed above will not lend themselves to quick or easy analysis. In particular, the issue of what interventions work to improve outcomes for children with disabilities is difficult and elusive. Interventions can achieve different outcomes depending on the child, the impairment, and the family's circumstances.

Second, research to address all the questions should have a strong family-centered focus. Families are among the most valuable sources of information about children with disabilities. They should be approached less as research subjects and more as informants with important understanding and insights to share.

Third, while the proposed questions target a larger group of children than those receiving SSI, the optimal structure of the SSI program depends heavily upon their answers. For this reason, the Social Security Administration should assume central responsibility for this research. Some questions can be addressed through manipulation of existing agency data,

¹ This final question relates more to values than to specific research. It is included because of its fundamental importance as the basis for public policy related to children with disabilities and their families.

Proposals for Research 110

while others will require involvement by other federal agencies and private research organizations. The Commission particularly encourages SSA to coordinate its efforts with federal agencies that interface with families, such as the Department of Health and Human Services and the Department of Education. However, SSA itself should assume responsibility for ensuring that the full range of questions is addressed.

Fourth, the Commission notes that children and adolescents, especially those with disabilities, have been consistently undervalued with respect to investment in research. The lapse extends not only to their use of medical and other services but to investment in the development of technology that could improve their functioning and participation in activities of daily life. The Commission believes that it is essential to increase attention to children and families in these areas of research.

Question I: Who Are Children with Disabilities?

The first and largest problem in developing a profile of children with disabilities is a conceptual one: there is no consensus on what disability is or how to measure it.² Without such consensus, national surveys and data bases rely on different criteria for measuring disability,³ and federal benefit programs employ widely differing eligibility requirements.⁴

Second, in the absence of regular and systematic collection of national data on children with disabilities, inquiry at the state and local level has proceeded in a piecemeal fashion. Study samples of children with disabilities are typically small and non-random. They provide little information on important subgroups of children with disabilities, such as infants and toddlers and those with mental health problems. There is also little information on the use of assistive technologies by children.

Third, findings from some studies may be skewed by adult respondent biases. For example, some research indicates that families are more likely to report conditions that affect their child's daily activities and less likely to report those that they consider embarrassing or stigmatizing.⁵ Other studies report substantial differences in the perspectives of three groups -- parents, teachers, and therapists -- in assessing children's intellectual functioning, social skills, and capacity for receptive and expressive communication.⁶

² Three major conceptual models of disability are: (1) the International Classification of Impairments, Disabilities and Handicaps (ICIDH), (2) a functional limitation framework developed by Saad Nagi, and (3) a relatively new functional assessment scale developed by Stein and Westbrook for the National Child Health Assessment Planning Project (NCHAPP).

³ For example, the National Health Interview Survey (NHIS) uses daily activity limitation, while the Survey of Income and Program Participation (SIPP) focuses on activities of daily living, instrumental activities of daily living, and functional limitation in a set of sensory and physical activities.

⁴ Federal laws and programs include more than 50 definitions of disability. These programs fall into eleven categories: education, employment, health, housing, income maintenance, rights, social services, vocational rehabilitation, taxation, veterans' benefits, and miscellaneous programs. C. Domzal, *Federal Statutory Definitions of Disability*. Falls Church, Virginia: Conwal Incorporated, February 1995.

⁵ For example, during a field testing of the NCHAPP, parents did not report that their children looked different from other children, even though staff reported the child had a visible disfigurement. R. Stein, & L. Westbrook, *Final Report of the National Child Health Assessment Planning Project: A planning proposal for a national survey of children with special health needs*. Bronx, NY: Division of General Pediatrics and the Preventive Intervention Research Center for Child Health, Albert Einstein College of Medicine/Montefiore Medical Center, 1993. Also see P.W. Newacheck and W.R. Taylor, "Childhood Chronic Illness: Prevalence, Severity and Impact," *American Journal of Diseases of Children*. 1992, Volume 145, p. 1367-1373.

⁶ Donald Bailey, Rune Simeonsson, Virginia Buysse, and Tina Smith, "Reliability of an Index of Child Characteristics;" *Developmental Medicine and Child Neurology*. 1993, Volume 35, p. 813.

These shortcomings of existing studies make it difficult to answer basic questions about children with disabilities. They do not provide systematic information on the costs of raising a child with a disability, the ways in which families cover these costs, the medical or nonmedical services that children use, how families spend SSI funds, or the evolution of children's impairments over time. By piecing existing studies together, however, one can observe a few recurrent patterns:

- * **Low-income families tend to spend most of a cash benefit on basic necessities.** Michelle Adler (1995; n = 7,200 families with children under 18 per year in 1991-1993 from the Consumer Expenditure Survey) found that expenditure patterns of families receiving SSI are similar to those of families receiving welfare (AFDC or general assistance), in that more than half of all expenditures are for food, clothing and shelter.⁷ Studies analyzing family support programs in three states (Louisiana: n = 483, Iowa: n = 120, and Michigan: n = 315) support the contention that low-income families tend to spend a cash benefit on essentials.⁸ A 1995 survey by The Arc of 954 families from 37 states showed that they typically spend their child's SSI benefit on a cluster of expenses related to meeting basic needs for food, clothing, and shelter.
- * **Beyond these basic expenditures, there is no typical spending profile.** Sandra Herman (1994; n = 315) found substantial inter-family variability in spending patterns among Michigan families. Disability-related purchases included special foods, day care services, adaptive equipment, educational aids, toys and recreational activities, transportation to medical appointments, medical bills not covered by other insurance, and clothing and other personal items for the child.
- * **The extent of children's disability-related needs is highly variable.** Maxfield and Kendall (1981; n = 1852) reported that only five percent of families had expenditures that exceeded their SSI benefit payment. Based on a review of national and community studies, Perrin, Shayne, and Bloom (1993) reported that chronically ill children make greater use of medical services than other children (2.7 times as many doctor visits and 14.5 times as many hospital days).⁹ Birenbaum and Cohen (1993; n = 326 children) found that the average health care expenditures for children with

⁷ Michelle Adler, "Expenditure Patterns for Families Receiving SSI: 1988-1993." Unpublished draft, May 1995.

⁸ K. Melda and J. Agosta, "Family Support Services in Louisiana." Human Services Research Institute, 1994. S. Herman, "Cash Subsidy Program: Family Satisfaction and Need," *Mental Retardation*, December 1994. J. Agosta, "Evaluating Family Support Services: Two Quantitative Case Studies," *Emerging Issues in Family Support*. Washington, D.C.: AAMR Monographs, 1992.

⁹ J. Perrin, M. Shayne, and S. Bloom, *Home and Community Care for Chronically Ill Children*. Oxford: Oxford University Press, 1993.

severe mental retardation are ten times higher than health care expenditures for all children.

- * **While a wide variety of services exist for children with disabilities, many families do not secure the help they need.** Knoll (1992; n = 92) found that less than half of surveyed families reported that their children received the disability and health-related services that they regarded as necessary.
- * **Disability has a major impact on families' lives.** Agosta, Deatherage, Bradley, and Keating (1991; n = 140 families) found that a child's disability affects a wide range of family decisions, including where to live, whether to continue education, and whether to accept job transfers or promotions.

Systematic national research is needed both to confirm these patterns from small, often selected populations and to answer the many basic questions they do not address. This research should focus on the following:

- * **What is the clinical status of children with disabilities?** Policy makers need a more robust and detailed classification of children's impairments. Of particular importance are:
 - What are the secondary impairments of children with multiple disabilities?
 - How extensively do children use basic medical services, such as primary and specialty medical/surgical care?
 - How extensively do children use other health care services, such as home care and nursing, therapies (occupational, physical therapy, speech, respiratory, and nutrition), genetic services, and EPSDT?
 - What medical supplies and medicines are purchased by families of children with disabilities?
- * **What is the functional status of children with disabilities?** In what ways, and to what extent, do children's impairments affect their ability to function in age appropriate ways?
 - What is their functional status in educational settings, including special education, early childhood/preschool programs, regular

Proposals for Research 114

education, tutoring, vocational training, transition to higher education, and community colleges, colleges, and universities?

- How extensively do these children use personal assistance services, including personal attendants, home maker services, and peer companions?
- What enabling services, such as transportation, home modifications, and assistive technology, are used by children with disabilities?
- How do these children utilize community services (either specialized or general), including recreational programs, summer camps, and sports?

* **What is the family status of children with disabilities** (defined to include impact on siblings)?

- What is the cost of raising a child with a disability? How do families cover these costs? What proportion of low-income families would be so if they did not have child with a disability?
- What proportion of parents withdraw from the workforce, take a less demanding job, or work fewer hours in order to care for a child with a disability? What proportion of parents of children receiving SSI are unable to work because of their child's special need for care?
- What disability-related expenditures do families incur? In particular, how do families spend the children's SSI benefits? What expenses do families incur beyond the amount of this benefit?
- What are the stresses of raising a child with a disability, and what is the psychological impact on the child and the family?

* **What is the status of children with disabilities as they grow and mature?**

- How remediable are children's impairments?
- What are the key transitions in the lives of children with disabilities, such as hospital to home, home to school, adolescence, graduation from high school, and school to community?

- What are their long-term pathways, including educational status and dependence on public programs?

* **How do children with disabilities compare to the broader population of American children without disabilities and to the narrower population of children with disabilities who receive SSI?**

- In particular, what is the potential universe of children in the general population who might become eligible for SSI using a variety of definitions?¹⁰

To obtain results that reflect the diversity of children of families, the research should determine how both vary according to several key classifications. For children, these classifications should include gender, age, clinical groupings (defined broadly by mental versus physical disability and narrowly by impairment type), as well as by whether the child's impairment has been diagnosed. For families, these classifications should include sociodemographic variables (economic status, household structure, employment status, cultural ethnic group), and health insurance status.

¹⁰ The Commission Task Force on Investments in Children examined existing studies which address this question and found a substantial range -- from 1.075 million to 1.775 million.

Question 2: What interventions are helpful (and harmful) in improving outcomes for children with disabilities?¹¹

Existing research focuses heavily on the efficacy of medical interventions. This focus should be broadened to include the following five categories:

- **medical care and related services**
 - primary and specialty medical/surgical care
 - other health care services (specialized therapies, e.g., occupational therapy, respiratory therapy, nutrition), home care, genetic services, and psychological services/counseling
- **personal assistance services**
- **technical supports and accommodations, including**
 - equipment
 - environmental accommodations
- **psychosocial interventions**
 - child
 - family and family support (including respite services)
 - coordination of care
- **educational services**
 - integration into schools
 - educational planning
 - regular and special education
 - in-school health services and access to education - In particular, what mechanisms are available to maximize families' access to the school-based health services they need, such as National School-Based Services funded by Medicaid?

An important, related question is whether efforts to coordinate these interventions (e.g., title V and special education programs) affect the quality of service provided to children and families, the level of families' satisfaction, or the outcomes that children achieve. If so, what approaches to service coordination are most effective?

Further, public funds are increasingly used to support private programs to serve children with disabilities, such as Medicaid contracts with private health organizations. Do efforts to coordinate these public and private resources aid children with disabilities and their families and, if so, how?

¹¹ Outcomes should be measured in terms of the status measures defined in question #1.

Finally, the Americans with Disabilities Act offers additional opportunities for individuals with disabilities. Its influence on children and adolescents and their transition to adulthood merits attention.

Question 3: Does the form in which support is provided (cash, direct services, or vouchers) affect outcomes for children with disabilities and their families and, if so, how?

At one level, in-kind services and cash benefits serve the same purpose -- providing general support for children with disabilities and their families. However, it is possible that the medium by which support is provided may influence outcomes for children with disabilities. The nature and extent of this difference are important issues for investigation.

Such investigations should examine three alternative (though not necessarily exclusive) means of providing assistance -- cash, direct services, and vouchers. Research should examine differences resulting from different means of providing assistance on the health and functioning of children and families. The main questions include:

- * Do these various forms of assistance provide different incentives for children and families with respect to long-term dependence or independence on public support?
- * Do different forms of assistance offer more or less flexibility with respect to meeting the complex and varied needs of children and their families?

In addition, research should compare these forms of assistance with respect to:

- the mix of goods and services offered and actually used by participants,
- satisfaction levels of program participants,
- the overall cost of service delivery, including the cost of administration,
- the extent of program overlap and interaction with other programs for children with disabilities, and
- the extent and mix of the population that is actually served.

This research should also address questions specific to each medium of support, such as:

- * **Vouchers** - How can a voucher program promote competition among providers? How can vouchers support sufficient flexibility to meet the varied needs of families whose children have very different disabilities?

* **Direct services** - How can support for direct services ensure adequately broad and accessible service options, coverage, coordination, and standards of care? Does the variety of providers and auspices of care affect the status of children with disabilities and their families?

* **Cash benefits** - How do families use their cash benefits? How does the need to maintain cash benefits affect families in positive and negative ways?

Finally, the research should determine how variations in SSA program administration affect the passage of children in and out of the SSI program (e.g., different ways and times of determining income eligibility, problems of under and over payment, and opportunities to diminish administrative costs). Currently many families go through complex maneuvers to meet monthly eligibility tests that would otherwise cause them to go on and off the program. Research is needed to identify alternatives that are more family-centered and that limit administrative costs.

Question 4: What outcomes should public support for children with disabilities and their families aim to achieve?

The answer to this question is critical to the formulation of effective public policy for children with disabilities and their families. However, it is difficult to answer this question because it involves equity, a concept whose definition varies widely from individual to individual.¹² The range of possible answers includes:

- Should support be aimed at making a family equally well off following the disability of a child as prior to this occurrence? If so, how should support levels be set? One approach would be to conduct an individualized, family-by-family calculation. Another would be to ask what a well-informed family with adequate income would purchase for their child with a disability. This raises the issues of what it means to be "well-informed" and what income should be treated as "adequate."
- Should public support be aimed at "leveling the playing field" between children with disabilities and those without disabilities, so that disability ceases to be a factor (so far as is technically feasible) in a child's achievement?¹³
- Should support be aimed at compensating for children's functional limitations in cases where it is cost-effective to do so from the taxpayers' perspective? If so, what factors should enter into the calculation of cost effectiveness? How should levels of compensation be set?
- Should support aim simply to provide basic medical care and a floor of income, without targeting particular outcomes beyond a subsistence level? Alternatively, should support be aimed at enabling a child with a disability to function in his or her family, school, and community, but not necessarily at the same level as a child without a disability (ex: *Westchester County v. Rowley* Supreme Court Decision)?

The Commission recognizes that these questions are fundamentally about values. However, their importance as a basis for public policy cannot be overstated.

¹² Research, such as production function studies, could help determine which outcomes are most achievable.

¹³ What is meant by "leveling the playing field" may vary from observer to observer. Generally, the Commission has taken a family perspective, defining equality in terms of family preferences.

Process Recommendations

In addition to developing a blueprint for future research, the Commission developed proposals for improving the quality of information collected through existing surveys and data bases. Implementation of these proposals will not fulfill the Commission's full research agenda. It will, however, fill some important information gaps. The recommendations are:

1. **Repeat on a regular basis the Disability Supplement of the National Health Interview Survey.** Implementation of the Disability Supplement of the NHIS began in January 1994 and will continue through 1995. The most comprehensive national survey of disability ever undertaken, it will provide extensive information about the severity of children's impairments, their use of medical services, family expenditures, receipt of SSI, unmet needs, and much more. The major missing element in the Disability Survey is information about changes in the population of children with disabilities over time. This survey should be repeated periodically to obtain this longitudinal data.
2. **Strengthen the Social Security Administration's research capacity.** As part of SSA's downsizing in the mid-1980s, the agency reduced its institutional capacity for research and policy analysis. As a result, it has limited information on children receiving SSI. Enhanced analytical capacity is particularly important now that SSA has been given independent status. Moreover, the great growth in the child and adolescent SSI program and the public interest in this program create a need for SSA to develop specific research capacities regarding children and adolescents, with trained staff dedicated to this purpose. SSA should also involve private researchers in this effort by funding and coordinating public-private research partnerships.
3. **Add questions about childhood disability to major national surveys.**
 - a. Revise the Consumer Expenditure Survey (CEX) to distinguish children who receive SSI childhood disability benefits from adult SSI beneficiaries. Sponsored by the Bureau of Labor Statistics, the CEX collects detailed annual consumer expenditure data from a variety of households. The CEX includes a question which identifies families with an SSI recipient, but it does not ask whether this individual is an adult or a child. The addition of this question to the CEX would provide this distinction, thus making available detailed information on the spending patterns of families of children receiving SSI.

- b. The Survey of Income and Program Participation (SIPP) includes information obtained from parents on children between the ages of three and 14. The SIPP has included data on children's disabilities since its inception, but none on children's SSI participation. This question should be added to the SIPP.
 - c. The National Medical Expenditure Survey (NMES) includes questions on the utilization and expenditures of families with disabilities. The sample sizes of children with disabilities are small, however. Increasing the size of these samples would increase the reliability of findings.
 - d. Questions on children with disabilities should be added to the decennial census by the Bureau of the Census.
 - e. The Current Population Survey (CPS) includes questions on disability resulting in inability to work for individuals over age 18. Questions should be added about children with disabilities, including family circumstances and receipt of SSI.
4. **Study the impact of restricting SSI eligibility for children.** If Congress enacts eligibility restrictions for the SSI program, it will be important to assess their effects. SSA should track the effects of these changes over time on children who lose SSI benefits, those who continue to receive SSI, and new SSI beneficiaries. In drawing this comparison, SSA should target such variables as health status, utilization of other federal and state benefit programs, family income, living conditions, and educational achievement.
5. **Capture additional data in Medicaid statistics.** Most states maintain substantial data regarding utilization of services by Medicaid recipients. Although some states identify the reason for Medicaid eligibility (e.g., receipt of SSI or AFDC), others do not. The Commission recommends the consistent use of an identifier indicating SSI status by all states. This would allow analyses of health care services utilization by children and adolescents receiving SSI, compared to other low-income children. Even though children and adolescents account for about 40 percent of all Medicaid recipients, relatively little research has addressed Medicaid utilization and utilization of other health care services by this population. The Commission recommends focused and ongoing attention to Medicaid research regarding children and adolescents, especially those with disabilities.

6. **Collect outcomes data on children in special education.** Over the past four years, the Outcomes Center at the University of Minnesota has been attempting to develop outcomes measures for children in special education. It has also been attempting to develop a national consensus on what such measures should be. In addition, SRI International has recently completed a major outcomes study for children in special education. Beyond these efforts, data on outcomes are sparse. Both the Department of Education and state education departments should accelerate their efforts to collect comprehensive outcomes data on children with disabilities.

Letters by Commission Members

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09/25/95

The Honorable Jim Slattery, Chairman
National Commission on Childhood Disability
801 Pennsylvania Avenue, N.W.
Room 625
Washington, D.C. 20004

Dear Chairman Slattery:

It is with great pleasure that I endorse the final report of the National Commission on Childhood Disability. My vote in support of the final report reflects my agreement with many, but certainly not all, of the recommendations contained in the report. It is impressive that a group of advocates, researchers and practitioners with diverse beliefs and viewpoints were able to forge a series of recommendations which, if implemented, would serve to strengthen an important program of support for children with disabilities residing in low-income families.

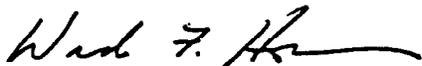
I do, nonetheless, wish to clarify several items. First, while it is true that no Commissioner either proposed or voted to replace the Children's SSI program with a voucher system, it would be inaccurate to conclude that there was no support within the Commission for examining the eventual replacement of the cash-based system with one utilizing vouchers. I, for one, did not proffer any proposals for a system of vouchers because I do not believe we have, as yet, adequate knowledge about how such a voucher system should be structured. As acknowledged in Chapter Five ("Alternative Forms of Support for Children with Disabilities"), there are some compelling reasons favoring the replacement of cash with vouchers. Nevertheless, we currently lack an adequate knowledge base upon which one could rely to structure such a system. As recommended in Chapter Seven ("Research for Future Policy Directions"), there is a need for further research to determine whether, and under what conditions, a voucher system might be a viable alternative to the Children's SSI program. Indeed, the Commission explicitly recognizes the possibility that for at least some children a voucher program is acceptable in its consensus recommendation that only Medicaid be provided to children who meet current SSI eligibility criteria but who would not meet the stricter standards proposed by the Commission.

Second, it is true the Commission did not find evidence that significant numbers of children were coached successfully to feign a disability in order to obtain SSI benefits. However, we were presented with no information as to the prevalence of children being coached unsuccessfully. This is an important issue because even unsuccessful coaching has costs associated with it. There are, for example, the financial costs to the administrators of the program who must expend funds to examine the applicant's claim. There are also psychological costs to the child when he or she is taught that it is permissible to try to deceive the government in order to obtain benefits. Unfortunately, there are simply no data available that address the issue of how much of a problem coaching is in this broader perspective.

Third, I voted against, and maintain strong objections to, the recommendation that parents of children with disabilities should be excluded from any time limit that is placed on welfare eligibility. This recommendation fails to recognize that not all children with disabilities require that their parent forgo paid work in order to care for the child. Allowing this blanket exemption would provide a further incentive for low-income parents to try to establish eligibility under the SSI program. In addition, such an exemption sends the message that if a family member has a disability, one should not be expected to follow the same rules as everyone else. While I strongly endorse the principle that a just and fair society supports and includes persons with disabilities, I do not believe that it is fair and just to issue wholesale exemptions based only upon the fact of a disability. I would be able to support such a recommendation if it had added the proviso that it pertained only to those parents whose presence was needed in the home to care for their child.

Despite these reservations, I do endorse the report as a whole. I am particularly appreciative of the leadership exerted by you as well as the exceptional work performed by Elaine Fultz, executive director, and her staff. It has been an honor to have been associated with the work of this Commission.

Sincerely,



Wade F. Horn, Ph.D.

STATEMENT OF DISSENT

PAUL MARCHAND

MEMBER, NATIONAL COMMISSION ON CHILDHOOD DISABILITY

I voted in opposition to the Report to Congress regarding Supplemental Security Income for Children with Disabilities as developed by the National Commission on Childhood Disability. Although there is much to support in the Report, the Commission's recommendation number three to "Strengthen the SSI Definition of Childhood Disability", if enacted by the Congress, would do irreparable harm to the SSI program and to tens of thousands of children with severe disabilities from low income families. Indeed, depending on which of the two options on the definition would be chosen, between 110,000 and 260,000 current and future (over the next five years) children who are SSI beneficiaries would be dropped or blocked from the program. Given what the Commission learned about the strengths and the flaws of the SSI children's program and the myriad other Commission recommendations aimed at rectifying those flaws, far too much harm will come to innocent children and families who have done nothing to deserve elimination from the vital benefits available from SSI.

In regards to eligibility, the Commission concluded that there was a miniscule amount of parental "coaching" and that some types of disabilities lent themselves to possible double counting in determining limitations of function under the Individual Functional Assessment process. I heartily agree that both of these problems must be addressed and the Commission's recommendations adequately do so in other parts of the report. In my opinion, implementation of recommendation number three will disqualify far more children than is necessary to rectify the valid concerns about the program. Simply put, the Commission creates too many sacrificial lambs.

I support the remaining recommendations. However, on balance, the deleterious effects of recommendation number three thwart, for too many children, the potential good realized by all of the other recommendations. I regret having to take this action. Throughout the Commission's deliberations, I reminded myself and sometimes my fellow Commissioners of Secretary Shalala's warning and challenge to us as we began our work which was, to paraphrase her, "Do as little harm as possible to those children who are truly eligible". By my vote, I sincerely hope I have met that test.

SAFE

SCHOOLS ARE FOR EVERYONE

A national coalition for integration of all students with disabilities through supported education

October 5, 1995

The Honorable James Slattery, Chairman
National Commission on Childhood Disability
801 Pennsylvania Avenue, N.W.
Room 625
Washington, D.C. 20004

Dear Mr. Slattery:

I came to this commission as an individual with three perspectives that as a parent of a child challenged with Down Syndrome, a former recipient of SSI and a professional social worker. As such I have struggled to understand the allegations of "coaching" by parents, of "gaming" the system as an SSI recipient, and the matter of not providing for children and families the preventive social services they so much need.

Much information was made available to us in order to address these concerns and others. Having studied the material provided, deliberated with my peers on the commission, and acknowledging the testimony of many individuals, including families, I cannot support the report as a whole. I make exception to what we were previously addressing as the pro family recommendations, these being items 1 through 2f of chapter 4 of the report to Congress of the National Commission on Childhood Disability. I also support chapter 7, Research For Future Policy Directions, for as explained in this chapter children with disabilities and their families have largely been neglected from research that could improve their lives.

Sharing life with families such as those that testified and having had the opportunity to address national policy which affects all of our lives confirms for me that much is still to be done to support ALL families. I hope and pray that Congress considers such advisement for if they do we will gain as a nation and not fail those who need support.

It was an honor to have had the opportunity to work with all commission members and a very competent staff led by Elaine Fultz, Ph.D.

Sincerely,



M. Carmen S. Ramirez

cc: Donna Shalala, Ph.D., Secretary, Department of Health and Human Services
Shirley Sears Chater, Ph.D., Commissioner, Social Security Administration



October 10, 1995

Secretary of Health and Human Services Donna Shalala
Hon. James Slattery, Chairman
Members, National Commission on Childhood Disability
Washington, D.C.

Re: Reservations, Understandings, and Dissent from Final Report
of National Commission on Childhood Disability

Dear Secretary Shalala and Fellow Commissioners:

I regret that the protocol of the Commission obliges me to vote either for or against the final Report and does not permit me to indicate my support, with reservations and understandings, of most of the Report and to indicate my dissent from a portion of the Report.

Given that forced choice, I must and do dissent and vote to NOT endorse the Report.

I set out below, however, my general support, reservations and understandings, and dissent from a portion.

I. General Support

On the whole, the Report merits the support of members of Congress and the Administration.

The Report discharges the Congressional mandate. More than that, it proposes carefully considered, sufficiently justified, and narrowly tailored changes in the administration of the SSI for children program.

I believe that the changes that the Commission recommends will -- on the whole -- benefit the children and families assisted through the SSI for children program.

II. Reservations, Understandings, and Dissent

A. Reservations.

I have a reservation about the aspect of the Report (chapter three, section entitled "The Commission") that describes the "several themes" that marked the Commission's discussions and analysis.

October 10, 1995

Page 2

The Report says that the Commission was concerned to structure the SSI program to "motivate, not deter, parents in encouraging their children to overcome their disabilities." I believe we were motivated by a desire to recommend improvements that would not create a disincentive to parents to receive appropriate interventions for their children; I do not believe that, on the whole, parents need to be motivated to seek treatment, and I do not believe that all disabilities can always be "overcome."

I also believe that the Commission was intensely focused on the issue of the eligible beneficiaries. Recommendation #3 in the Report reflects this intensity.

Finally, I believe the Commission's concerns to bring greater accountability to the SSI program masks the extensive hearings and deliberations we had about alleged gaming of the SSI application and award system. We should be explicit: we looked hard at a wealth of evidence and heard a great deal of testimony about gaming and concluded that the evidence does not match the media or somewhat limited public/Congressional concerns.

B. Understandings.

I believe that the Commission explicitly and unreservedly approved an SSI program that awards cash to families. It did not approve any so-called voucher or other alternative medium of SSI benefits, with the exception that Medicaid benefits constitute an alternative medium. To quote from one of our Commissioners, "Cash is king" so far as the Commission is concerned.

Turning now to the Commission's recommendations for research, I had hoped that these recommendations would relate to only the SSI program and not be a comprehensive proposal for federal research related to children (or adults) with disabilities and their families. Since they appear to be more than that, I have to demur.

Also with respect to the Commission's recommendations for research, I believe that SSA-sponsored research should focus on the provider system as an indispensable variable affecting families' and children's well-being and behaviors when they receive SSI benefits. A family and child are not isolates; their well-being depends as much on their own behavior as on that of programs (governmental and nongovernmental) and policies.

October 10, 1995
Page 3

III. Dissent

I cannot support one of the Commission's recommendations and I dissent from the entire Report because of this one recommendation.

It is the one that is, in my judgment, the most significant in its impact on the children and families, and it is the one that will have the most deleterious effects on them.

I refer to Recommendation #3, "Recommendations to Strengthen the SSI Definition of Childhood Disability."

This recommendation is cast as one to "strengthen the SSI definition of childhood disability." It consists of a statement on "Areas of Agreement" among the Commissioners; a proposal to change the statutory definition of eligible children (Option One); and a proposal to change the regulatory process for admitting children to the rolls (Option Two).

I think that it is a mischaracterization to refer to Recommendation #3 as one that "strengthens" the SSI eligibility criteria. As operationalized, each Option would significantly reduce the number of eligible beneficiaries. I hardly regard that action as strengthening.

One Option, which I opposed, would reduce the number of eligible beneficiaries by approximately 260,000 children or 20% of the current caseload over five years. That is far too great a reduction, given the Social Security Administration's recent record in monitoring admission to the rolls, the overwhelming evidence that there is no provable gaming of the eligibility-admission procedures, and the narrowly tailored and carefully crafted improvements that the Commission recommends in the administration of the program.

Another Option, which I supported because it was the only one the Commission considered as an alternative to the 260,000-child cut, would reduce the number of eligible beneficiaries by approximately 110,000 children or 8% of the current caseload over five years. Again, that itself is far too great a reduction in light of the factors I described in the paragraph above.

I cannot accept the conclusion of Recommendation #3 that a child with three "moderate" impairments (currently, that child is admissible to the rolls) is not a child with a severe disability or combinations of disabilities; and I cannot accept the conclusion that follows from that determination, namely, that the

October 10, 1995

Page 4

child and the child's family are unworthy of federal cash support to satisfy the four purposes of the SSI program as the Commission properly describes them in another recommendation.

Such a child is indeed one who -- by every noninvidious policy decision that the federal government and the state governments have made in the last 30 years -- has a severe disability, faces extraordinary difficulties in securing (much less taking advantage of) opportunities for independence, participation in and contribution to America, and integration and inclusion in the full panoply of American life.

And such a child is one who -- in my professional experience and personal history as the parent of a young man with mental retardation and autism -- is especially meritorious of our support.

Add to that child's disability-related challenges the fact that the child's family meets the federal definitions of poverty, and one has a child and family who should not be eliminated from the SSI program.

I cannot support Recommendation #3 with respect to its two reformulations of the eligible class of beneficiaries. It is intolerable for me, given all I have done and have yet to do with and for people with disabilities and their families, to accept any -- repeat: any -- proposal that reduces the number of eligible beneficiaries.

I do support the three "Areas of Agreement" described under Options for Change in Recommendation #3 (eliminating double counting, providing Medicaid, and following a presumption of admission to the rolls).

Indeed, it is because the Commission has a wide area of agreement on these and other specific improvements that I support the rest of the Report. To reiterate: given the forced choice of full support or dissent from the Report as a whole, I dissent.

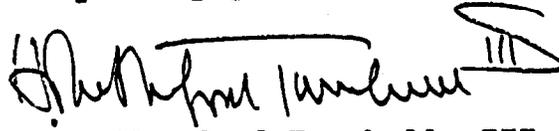
IV. Appreciations

Because I respect the capacities, energy, and steadfastness that my fellow Commissioners brought to our difficult and highly controversial work, and because I value those prior-existing friendships that endured our work and the new ones that developed as a result of it, I say that it has been an honor to have served

October 10, 1995
Page 5

with the Commission and to have been directed in our work by Jim Slattery and assisted by such capable staff. To my fellow Commissioners and the staff, I tender my grateful and sincere appreciation.

Very truly yours,

A handwritten signature in cursive script, reading "H. Rutherford Turnbull, III". The signature is written in dark ink and includes a stylized flourish at the end.

H. Rutherford Turnbull, III

APPENDICES

<i>Commission Statute</i>	Appendix 1
<i>Commission Member Profiles</i>	Appendix 2
<i>Members of Congress, Administration Officials, Public Witnesses, and Expert Panels Who Addressed the Commission</i>	Appendix 3
* <i>Members of Congress and Administration Officials</i>	3-A
* <i>Public Witnesses</i>	3-B
* <i>Expert Panels</i>	3-C
<i>References</i>	Appendix 4
* <i>Books</i>	4-A
* <i>Journals and Periodicals</i>	4-B
* <i>Newspaper Articles</i>	4-C
* <i>Reports and Working Papers</i>	4-D
* <i>Social Security Administration Guides and Pamphlets</i>	4-E
* <i>Sullivan v. Zebley Supreme Court Decision</i>	4-F
<i>Senator Bob Packwood's Letter to Chairman Slattery and the Commission's Preliminary Recommendations</i>	Appendix 5
<i>Actuarial Estimates</i>	Appendix 6
* <i>Social Security Administration's Actuarial Estimates of Effects of Commission Recommendations on SSI Program</i>	6-A
* <i>Health Care Financing Administration's Estimated Medicaid Savings Due to Commission's Proposed Changes to Definition of Childhood Disability</i>	6-B
<i>Charts</i>	Appendix 7
* <i>Proposal to Modify the Definition of SSI Childhood Disability in HR 4</i>	7-A
* <i>Initial Determinations, Calendar Year 1994, A Comparison of Arkansas, Kansas, and Louisiana</i>	7-B
* <i>Estimated SSI Program Growth Under Two Alternatives for Revising the Definition of Disability</i>	7-C
* <i>SSI Childhood Disability Determinations: Initial Claims-Initial Allowances, February 11, 1991-December 31, 1994</i>	7-D
* <i>SSI Childhood Disability Determinations: Initial Allowance Impairment Groupings by Nation and State, February 11, 1991-December 31, 1994</i>	7-E
* <i>SSI Childhood Disability Determinations: Initial Claims-Initial Level Allowances-Primary Impairment by Regulation Basis, February 11, 1991-December 31, 1994</i>	7-F

APPENDICES—cont.

***Paper by Elizabeth Boggs, Ph.D.—"Balancing Equity and Efficiency:
Potential Improvements in SSI"***

Appendix 8

Individualized Functional Assessment Form

Appendix 9

Social Security Independence and Program Improvements Act of 1994

Appendix 1

SEC. 202. COMMISSION ON CHILDHOOD DISABILITY.

(a) **ESTABLISHMENT OF COMMISSION.**—The Secretary of Health and Human Services (in this section referred to as the “Secretary”) shall appoint a Commission on the Evaluation of Disability in Children (in this section referred to as the “Commission”).

(b) **APPOINTMENT OF MEMBERS.**—(1) The Secretary shall appoint not less than 9 but not more than 15 members to the Commission, including—

(A) recognized experts in the field of medicine, whose work involves—

(i) the evaluation and treatment of disability in children;

(ii) the study of congenital, genetic, or perinatal disorders in children; or

(iii) the measurement of developmental milestones and developmental deficits in children; and

(B) recognized experts in the fields of—

(i) psychology;

(ii) education and rehabilitation;

(iii) law;

(iv) the administration of disability programs; and

(v) social insurance (including health insurance); and

(C) other fields of expertise that the Secretary determines to be appropriate.

(2) Members shall be appointed by January 1, 1995, without regard to the provisions of title 5, United States Code, governing appointments to competitive service.

(3) Members appointed under this subsection shall serve for a term equivalent to the duration of the Commission.

(4) The Secretary shall designate a member of the Commission to serve as Chair of the Commission for a term equivalent to the duration of the Commission.

(c) **ADMINISTRATIVE PROVISIONS.**—(1) Service as a member of the Commission by an individual who is not otherwise a Federal employee shall not be considered service in an appointive or elective position in the Federal Government for the purposes of title 5, United States Code.

(2) Each member of the Commission who is not a full-time Federal employee shall be paid compensation at a rate equal to the daily equivalent of the rate of basic pay in effect for Level IV of the Executive Schedule for each day (including travel time) the member attends meetings or otherwise performs the duties of the Commission.

(3) While away from their homes or regular places of business on the business of the Commission, each member who is not a full-time Federal employee may be allowed travel expenses, including per diem in lieu of subsistence, as authorized by section 5703 of title 5, United States Code, for persons employed intermittently in the Government service.

(d) **ASSISTANCE TO COMMISSION.**—The Commission may engage individuals skilled in medical and other aspects of childhood disability to provide such technical assistance as may be necessary to carry out the functions of the Commission. The Secretary shall make available to the Commission such secretarial, clerical, and other assistance as the Commission may require to carry out the functions of the Commission.

Appendix 1

(e) **STUDY BY THE COMMISSION.**—(1) The Commission shall conduct a study, in consultation with the National Academy of Sciences, of the effects of the definition of “disability” under title XVI of the Social Security Act (42 U.S.C. 1382 et seq.) in effect on the date of enactment of this Act, as such definition applies to determining whether a child under the age of 18 is eligible to receive benefits under such title, the appropriateness of such definition, and the advantages and disadvantages of using any alternative definition of disability in determining whether a child under age 18 is eligible to receive benefits under such title.

(2) The study described in paragraph (1) shall include issues of—

(A) whether the need by families for assistance in meeting high costs of medical care for children with serious physical or mental impairments, whether or not they are eligible for disability benefits under title XVI of the Social Security Act, might appropriately be met through expansion of Federal health assistance programs;

(B) the feasibility of providing benefits to children through noncash means, including but not limited to vouchers, debit cards, and electronic benefit transfer systems;

(C) the extent to which the Social Security Administration can involve private organizations in an effort to increase the provision of social services, education, and vocational instruction with the aim of promoting independence and the ability to engage in substantial gainful activity;

(D) alternative ways and providing retroactive supplemental security income benefits to disabled children, including the desirability and feasibility of conserving some portion of such benefits to promote the long-term well-being of such children;

(E) the desirability and methods of increasing the extent to which benefits are used in the effort to assist disabled children in achieving independence and engaging in substantial gainful activity;

(F) the effects of the supplemental security income program on disabled children and their families; and

(G) such other issues that the Secretary determines to be appropriate.

(f) **REPORT.**—Not later than November 30, 1995, the Commission shall prepare a report and submit such report to the Committee on Ways and Means of the House of Representatives and the Committee on Finance of the Senate which shall summarize the results of the study described in subsection (e) and include any recommendations that the Commission determines to be appropriate.

These shortcomings of existing studies make it difficult to answer basic questions about children with disabilities. They do not provide systematic information on the costs of raising a child with a disability, the ways in which families cover these costs, the medical or nonmedical services that children use, how families spend SSI funds, or the evolution of children's impairments over time. By piecing existing studies together, however, one can observe a few recurrent patterns:

- * **Low-income families tend to spend most of a cash benefit on basic necessities.** Michelle Adler (1995; n = 7,200 families with children under 18 per year in 1991-1993 from the Consumer Expenditure Survey) found that expenditure patterns of families receiving SSI are similar to those of families receiving welfare (AFDC or general assistance), in that more than half of all expenditures are for food, clothing and shelter.⁷ Studies analyzing family support programs in three states (Louisiana: n = 483, Iowa: n = 120, and Michigan: n = 315) support the contention that low-income families tend to spend a cash benefit on essentials.⁸ A 1995 survey by The Arc of 954 families from 37 states showed that they typically spend their child's SSI benefit on a cluster of expenses related to meeting basic needs for food, clothing, and shelter.
- * **Beyond these basic expenditures, there is no typical spending profile.** Sandra Herman (1994; n = 315) found substantial inter-family variability in spending patterns among Michigan families. Disability-related purchases included special foods, day care services, adaptive equipment, educational aids, toys and recreational activities, transportation to medical appointments, medical bills not covered by other insurance, and clothing and other personal items for the child.
- * **The extent of children's disability-related needs is highly variable.** Maxfield and Kendall (1981; n = 1852) reported that only five percent of families had expenditures that exceeded their SSI benefit payment. Based on a review of national and community studies, Perrin, Shayne, and Bloom (1993) reported that chronically ill children make greater use of medical services than other children (2.7 times as many doctor visits and 14.5 times as many hospital days).⁹ Birenbaum and Cohen (1993; n = 326 children) found that the average health care expenditures for children with

⁷ Michelle Adler, "Expenditure Patterns for Families Receiving SSI: 1988-1993." Unpublished draft, May 1995.

⁸ K. Melda and J. Agosta, "Family Support Services in Louisiana." Human Services Research Institute, 1994. S. Herman, "Cash Subsidy Program: Family Satisfaction and Need," *Mental Retardation*, December 1994. J. Agosta, "Evaluating Family Support Services: Two Quantitative Case Studies," *Emerging Issues in Family Support*. Washington, D.C.: AAMR Monographs, 1992.

⁹ J. Perrin, M. Shayne, and S. Bloom, *Home and Community Care for Chronically Ill Children*. Oxford: Oxford University Press, 1993.

severe mental retardation are ten times higher than health care expenditures for all children.

- * **While a wide variety of services exist for children with disabilities, many families do not secure the help they need.** Knoll (1992; n = 92) found that less than half of surveyed families reported that their children received the disability and health-related services that they regarded as necessary.
- * **Disability has a major impact on families' lives.** Agosta, Deatherage, Bradley, and Keating (1991; n = 140 families) found that a child's disability affects a wide range of family decisions, including where to live, whether to continue education, and whether to accept job transfers or promotions.

Systematic national research is needed both to confirm these patterns from small, often selected populations and to answer the many basic questions they do not address. This research should focus on the following:

- * **What is the clinical status of children with disabilities?** Policy makers need a more robust and detailed classification of children's impairments. Of particular importance are:
 - What are the secondary impairments of children with multiple disabilities?
 - How extensively do children use basic medical services, such as primary and specialty medical/surgical care?
 - How extensively do children use other health care services, such as home care and nursing, therapies (occupational, physical therapy, speech, respiratory, and nutrition), genetic services, and EPSDT?
 - What medical supplies and medicines are purchased by families of children with disabilities?
- * **What is the functional status of children with disabilities?** In what ways, and to what extent, do children's impairments affect their ability to function in age appropriate ways?
 - What is their functional status in educational settings, including special education, early childhood/preschool programs, regular

Proposals for Research 114

education, tutoring, vocational training, transition to higher education, and community colleges, colleges, and universities?

- How extensively do these children use personal assistance services, including personal attendants, home maker services, and peer companions?
- What enabling services, such as transportation, home modifications, and assistive technology, are used by children with disabilities?
- How do these children utilize community services (either specialized or general), including recreational programs, summer camps, and sports?

* **What is the family status of children with disabilities** (defined to include impact on siblings)?

- What is the cost of raising a child with a disability? How do families cover these costs? What proportion of low-income families would be so if they did not have child with a disability?
- What proportion of parents withdraw from the workforce, take a less demanding job, or work fewer hours in order to care for a child with a disability? What proportion of parents of children receiving SSI are unable to work because of their child's special need for care?
- What disability-related expenditures do families incur? In particular, how do families spend the children's SSI benefits? What expenses do families incur beyond the amount of this benefit?
- What are the stresses of raising a child with a disability, and what is the psychological impact on the child and the family?

* **What is the status of children with disabilities as they grow and mature?**

- How remediable are children's impairments?
- What are the key transitions in the lives of children with disabilities, such as hospital to home, home to school, adolescence, graduation from high school, and school to community?

- What are their long-term pathways, including educational status and dependence on public programs?

* **How do children with disabilities compare to the broader population of American children without disabilities and to the narrower population of children with disabilities who receive SSI?**

- In particular, what is the potential universe of children in the general population who might become eligible for SSI using a variety of definitions?¹⁰

To obtain results that reflect the diversity of children of families, the research should determine how both vary according to several key classifications. For children, these classifications should include gender, age, clinical groupings (defined broadly by mental versus physical disability and narrowly by impairment type), as well as by whether the child's impairment has been diagnosed. For families, these classifications should include sociodemographic variables (economic status, household structure, employment status, cultural ethnic group), and health insurance status.

¹⁰ The Commission Task Force on Investments in Children examined existing studies which address this question and found a substantial range -- from 1.075 million to 1.775 million.

Question 2: What interventions are helpful (and harmful) in improving outcomes for children with disabilities?¹¹

Existing research focuses heavily on the efficacy of medical interventions. This focus should be broadened to include the following five categories:

- medical care and related services

- primary and specialty medical/surgical care
- other health care services (specialized therapies, e.g., occupational therapy, respiratory therapy, nutrition), home care, genetic services, and psychological services/counseling

- personal assistance services

- technical supports and accommodations, including

- equipment
- environmental accommodations

- psychosocial interventions

- child
- family and family support (including respite services)
- coordination of care

- educational services

- integration into schools
- educational planning
- regular and special education
- in-school health services and access to education - In particular, what mechanisms are available to maximize families' access to the school-based health services they need, such as National School-Based Services funded by Medicaid?

An important, related question is whether efforts to coordinate these interventions (e.g., title V and special education programs) affect the quality of service provided to children and families, the level of families' satisfaction, or the outcomes that children achieve. If so, what approaches to service coordination are most effective?

Further, public funds are increasingly used to support private programs to serve children with disabilities, such as Medicaid contracts with private health organizations. Do efforts to coordinate these public and private resources aid children with disabilities and their families and, if so, how?

¹¹ Outcomes should be measured in terms of the status measures defined in question #1.

Finally, the Americans with Disabilities Act offers additional opportunities for individuals with disabilities. Its influence on children and adolescents and their transition to adulthood merits attention.

Question 3: Does the form in which support is provided (cash, direct services, or vouchers) affect outcomes for children with disabilities and their families and, if so, how?

At one level, in-kind services and cash benefits serve the same purpose -- providing general support for children with disabilities and their families. However, it is possible that the medium by which support is provided may influence outcomes for children with disabilities. The nature and extent of this difference are important issues for investigation.

Such investigations should examine three alternative (though not necessarily exclusive) means of providing assistance -- cash, direct services, and vouchers. Research should examine differences resulting from different means of providing assistance on the health and functioning of children and families. The main questions include:

- * Do these various forms of assistance provide different incentives for children and families with respect to long-term dependence or independence on public support?
- * Do different forms of assistance offer more or less flexibility with respect to meeting the complex and varied needs of children and their families?

In addition, research should compare these forms of assistance with respect to:

- the mix of goods and services offered and actually used by participants,
- satisfaction levels of program participants,
- the overall cost of service delivery, including the cost of administration,
- the extent of program overlap and interaction with other programs for children with disabilities, and
- the extent and mix of the population that is actually served.

This research should also address questions specific to each medium of support, such as:

- * **Vouchers** - How can a voucher program promote competition among providers? How can vouchers support sufficient flexibility to meet the varied needs of families whose children have very different disabilities?

* **Direct services** - How can support for direct services ensure adequately broad and accessible service options, coverage, coordination, and standards of care? Does the variety of providers and auspices of care affect the status of children with disabilities and their families?

* **Cash benefits** - How do families use their cash benefits? How does the need to maintain cash benefits affect families in positive and negative ways?

Finally, the research should determine how variations in SSA program administration affect the passage of children in and out of the SSI program (e.g., different ways and times of determining income eligibility, problems of under and over payment, and opportunities to diminish administrative costs). Currently many families go through complex maneuvers to meet monthly eligibility tests that would otherwise cause them to go on and off the program. Research is needed to identify alternatives that are more family-centered and that limit administrative costs.

Question 4: What outcomes should public support for children with disabilities and their families aim to achieve?

The answer to this question is critical to the formulation of effective public policy for children with disabilities and their families. However, it is difficult to answer this question because it involves equity, a concept whose definition varies widely from individual to individual.¹² The range of possible answers includes:

- Should support be aimed at making a family equally well off following the disability of a child as prior to this occurrence? If so, how should support levels be set? One approach would be to conduct an individualized, family-by-family calculation. Another would be to ask what a well-informed family with adequate income would purchase for their child with a disability. This raises the issues of what it means to be "well-informed" and what income should be treated as "adequate."
- Should public support be aimed at "leveling the playing field" between children with disabilities and those without disabilities, so that disability ceases to be a factor (so far as is technically feasible) in a child's achievement?¹³
- Should support be aimed at compensating for children's functional limitations in cases where it is cost-effective to do so from the taxpayers' perspective? If so, what factors should enter into the calculation of cost effectiveness? How should levels of compensation be set?
- Should support aim simply to provide basic medical care and a floor of income, without targeting particular outcomes beyond a subsistence level? Alternatively, should support be aimed at enabling a child with a disability to function in his or her family, school, and community, but not necessarily at the same level as a child without a disability (ex: *Westchester County v. Rowley* Supreme Court Decision)?

The Commission recognizes that these questions are fundamentally about values. However, their importance as a basis for public policy cannot be overstated.

¹² Research, such as production function studies, could help determine which outcomes are most achievable.

¹³ What is meant by "leveling the playing field" may vary from observer to observer. Generally, the Commission has taken a family perspective, defining equality in terms of family preferences.

Process Recommendations

In addition to developing a blueprint for future research, the Commission developed proposals for improving the quality of information collected through existing surveys and data bases. Implementation of these proposals will not fulfill the Commission's full research agenda. It will, however, fill some important information gaps. The recommendations are:

- 1. Repeat on a regular basis the Disability Supplement of the National Health Interview Survey.** Implementation of the Disability Supplement of the NHIS began in January 1994 and will continue through 1995. The most comprehensive national survey of disability ever undertaken, it will provide extensive information about the severity of children's impairments, their use of medical services, family expenditures, receipt of SSI, unmet needs, and much more. The major missing element in the Disability Survey is information about changes in the population of children with disabilities over time. This survey should be repeated periodically to obtain this longitudinal data.
- 2. Strengthen the Social Security Administration's research capacity.** As part of SSA's downsizing in the mid-1980s, the agency reduced its institutional capacity for research and policy analysis. As a result, it has limited information on children receiving SSI. Enhanced analytical capacity is particularly important now that SSA has been given independent status. Moreover, the great growth in the child and adolescent SSI program and the public interest in this program create a need for SSA to develop specific research capacities regarding children and adolescents, with trained staff dedicated to this purpose. SSA should also involve private researchers in this effort by funding and coordinating public-private research partnerships.
- 3. Add questions about childhood disability to major national surveys.**
 - a. Revise the Consumer Expenditure Survey (CEX) to distinguish children who receive SSI childhood disability benefits from adult SSI beneficiaries. Sponsored by the Bureau of Labor Statistics, the CEX collects detailed annual consumer expenditure data from a variety of households. The CEX includes a question which identifies families with an SSI recipient, but it does not ask whether this individual is an adult or a child. The addition of this question to the CEX would provide this distinction, thus making available detailed information on the spending patterns of families of children receiving SSI.

- b. The Survey of Income and Program Participation (SIPP) includes information obtained from parents on children between the ages of three and 14. The SIPP has included data on children's disabilities since its inception, but none on children's SSI participation. This question should be added to the SIPP.
 - c. The National Medical Expenditure Survey (NMES) includes questions on the utilization and expenditures of families with disabilities. The sample sizes of children with disabilities are small, however. Increasing the size of these samples would increase the reliability of findings.
 - d. Questions on children with disabilities should be added to the decennial census by the Bureau of the Census.
 - e. The Current Population Survey (CPS) includes questions on disability resulting in inability to work for individuals over age 18. Questions should be added about children with disabilities, including family circumstances and receipt of SSI.
4. **Study the impact of restricting SSI eligibility for children.** If Congress enacts eligibility restrictions for the SSI program, it will be important to assess their effects. SSA should track the effects of these changes over time on children who lose SSI benefits, those who continue to receive SSI, and new SSI beneficiaries. In drawing this comparison, SSA should target such variables as health status, utilization of other federal and state benefit programs, family income, living conditions, and educational achievement.
5. **Capture additional data in Medicaid statistics.** Most states maintain substantial data regarding utilization of services by Medicaid recipients. Although some states identify the reason for Medicaid eligibility (e.g., receipt of SSI or AFDC), others do not. The Commission recommends the consistent use of an identifier indicating SSI status by all states. This would allow analyses of health care services utilization by children and adolescents receiving SSI, compared to other low-income children. Even though children and adolescents account for about 40 percent of all Medicaid recipients, relatively little research has addressed Medicaid utilization and utilization of other health care services by this population. The Commission recommends focused and ongoing attention to Medicaid research regarding children and adolescents, especially those with disabilities.

6. **Collect outcomes data on children in special education.** Over the past four years, the Outcomes Center at the University of Minnesota has been attempting to develop outcomes measures for children in special education. It has also been attempting to develop a national consensus on what such measures should be. In addition, SRI International has recently completed a major outcomes study for children in special education. Beyond these efforts, data on outcomes are sparse. Both the Department of Education and state education departments should accelerate their efforts to collect comprehensive outcomes data on children with disabilities.

