

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.

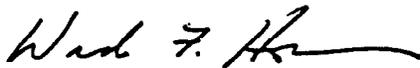
I do, nonetheless, wish to clarify several items. First, while it is true that no Commissioner either proposed or voted to replace the Children's SSI program with a voucher system, it would be inaccurate to conclude that there was no support within the Commission for examining the eventual replacement 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,

A handwritten signature in cursive script, appearing to read "Wade F. Horn".

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:

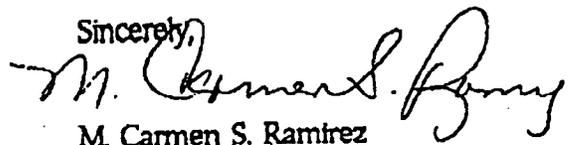
I came to this commission as an individual with three perspectives that as a parent of a child challenged with Down Syndrome, a former recipient of SSI and a professional social worker. As such I have struggled to understand the allegations of "coaching" by parents, of "gaming" the system as an SSI recipient, 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.

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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.

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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

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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.

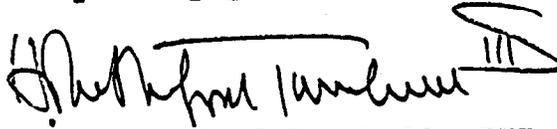
IV. Appreciations

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

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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