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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.

Members of the National Commission on Childhood Disability

* *Polly Arango* is the parent of four children, one of whom has multiple disabilities. She is a co-founder and the director of Family Voices, a national grassroots network of families and friends speaking on behalf of children with special health care needs. She sits on local, state, and national boards related to health, disability, children, and family issues, and is the author of many articles about children with special needs and their families.

* *Adrienne Asch, Ph.D.*, is the Henry R. Luce Professor of Biology, Ethics, and the Politics of Human Reproduction at Wellesley College, Wellesley, Massachusetts. Dr. Asch is an ethicist and social psychologist who has researched legal and ethical problems in health care delivery. She has written extensively on disability, bioethics, and reproductive technology.

* *Dolores Berkovsky, MSN, LMSW*, is Director of Children's Services at Catholic Charities of Fort Worth, Texas. Ms. Berkovsky is responsible for a large continuum of child and family services, including programs for residential treatment, family preservation, foster care, adoption of children with disabilities, out-patient assessment, and treatment services.

* *Wade F. Horn, Ph.D.*, is Director of the National Fatherhood Initiative, a group that promotes enhancing the role of the father in families. Dr. Horn is a clinical child psychologist and a nationally recognized expert on Attention Deficit Hyperactivity Disorder. In 1993, Dr. Horn served as the National Executive Director of Children and Adults with Attention Deficit Disorders. During the Bush Administration, he served as the Commissioner for Children, Youth, and Families and chief of the Children's Bureau in the Administration for Children and Families. Dr. Horn also served as a Presidential appointee to the National Commission on Children from 1989 to 1993.

* *Jennifer Howse, Ph.D.*, is President of the March of Dimes Birth Defects Foundation. Dr. Howse previously served as Associate Commissioner for the Office of Mental Retardation and Developmental Disabilities for the State of New York. She also has served as the Executive Director of the Greater New York March of Dimes and the Pennsylvania State Commission for Mental Retardation.

* *Sharman Davis Jamison* is the coordinator of two national technical assistance projects located at the Parent Advocacy Coalition Educational Rights (PACER) Center, both of which address family and consumer concerns about transition, supported employment, and the Rehabilitation Act. Ms. Jamison, the mother of an adult daughter who is autistic and deaf, is also a member of the President's Committee on Employment of Persons with Disabilities and the National Advisory Committee of the Howard University Research and Training Center.

Appendix 2

* *Dan Johnson* is Director of the Office for Persons with Physical Disabilities, Wisconsin Department of Health and Social Services. Mr. Johnson is responsible for the development and coordination of programs which provide the services essential to promote independence and self-sufficiency among persons with physical disabilities.

* *Paul Marchand* is Director of the National Governmental Affairs Office of The Arc. He is a leading spokesperson for children with mental impairments. Mr. Marchand actively assists Congress and federal agencies in formulating programs and benefits for individuals with mental retardation and their families. He also serves as the Chairman of the Consortium for Citizens with Disabilities, a Washington-based coalition of over 100 national disability organizations involved in public policy.

* *James M. Perrin, M.D.*, is an Associate Professor of Pediatrics at Harvard Medical School and Director of the Division of General Pediatrics at Massachusetts General Hospital in Boston, Massachusetts. Dr. Perrin has written extensively on the organization of services for children with chronic conditions and co-authored *Home and Community Care for Chronically Ill Children* and *Chronically Ill Children and Their Families*. He currently chairs the American Academy of Pediatrics Committee on Children with Disabilities.

* *M. Carmen S. Ramirez* is Founder and President of Schools Are for Everyone (SAFE), El Paso, Texas chapter. Ms. Ramirez volunteers extensively in her community and works on behalf of children with disabilities and their families. She is a member of the Executive Board for the Association of People with Severe Handicaps, the Texas Continuing Advisory Commission for Special Education, and the Governing Commission of the Texas Parent and Training Information Center for Latino Parents of Children with Disabilities.

* *Carol Rank, M.S., M.P.A.*, is Acting Director of the Kansas Disability Determination and Referral Service. Ms. Rank works closely with Kansas State Services for Children with Special Health Care Needs to help facilitate a better understanding of the eligibility requirements for the Supplemental Security Income program for children with disabilities.

* *Jim Slattery* is a former United States Representative from the Second District of Kansas. He currently is a partner in the law firm of Wiley, Rein, and Fielding. Mr. Slattery was elected to the House of Representatives in 1982 and served six terms. He served twelve years on the House Energy and Commerce Committee, where he was active on environmental, health care, telecommunications, and railroad issues. Mr. Slattery also served for six years on the House Budget Committee and was chairman of the House Veterans' Affairs Subcommittee on Compensation, Pension, and Insurance.

* ***Rud Turnbull, LL.B./J.D., LL.M.***, is Co-director of the Beach Center on Families and Disability, a rehabilitation research and training center at The University of Kansas, where he is also Professor of Special Education and Courtesy Professor of Law. Mr. Turnbull, the father of a son who has mental retardation and autism, is an expert and author in disability policy. He has served as President, American Association on Mental Retardation; Secretary, The Arc; Treasurer, The Association for Persons with Severe Disabilities; and Chairman, American Bar Association Commission on Mental and Physical Disability Law.

* ***Barbara Wolfe, Ph.D.***, is Director of the Institute for Research on Poverty at the University of Wisconsin, where she is also a member of the faculty of the Department of Economics, the Department of Preventive Medicine, and the LaFollette Institute of Public Affairs. Dr. Wolfe has authored a number of publications on health policy issues, including a book, *Succeeding Generations: On the Effect of Investments in Children*.

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