

## **FAMILY RESEARCH: LEAVE NO FAMILY BEHIND**

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### **A. National Goals**

#### **1. The Primary National Goal**

To support the caregiving efforts and to enhance the quality of life of all families so that families will remain the core unit of American society.

#### **2. National Goals Subsumed under the Primary National Goal**

- a. To ensure family-professional partnerships in research, policy-making, and the planning and delivery of supports and services to the end that families will have rights and opportunities to control their own destinies, with due regard to the autonomy of adult family members with disabilities to control their own lives.
- b. To ensure that families will have rights and opportunities to fully participate in communities of their choice and, to that end, that they will

have comprehensive, inclusive, and culturally responsive supports and services.

- c. To ensure that services and supports for all families will be available, accessible, appropriate, affordable, and accountable.
- d. To ensure that there are sufficient public and private funding mechanisms and levels to implement these goals and that all families will have rights and opportunities to direct the use of public funds authorized and appropriated for their benefit.
- e. To ensure that families and professionals will have full access to state-of-art knowledge and best practices and that they will have rights and opportunities to collaborate in utilizing the knowledge and those practices.

### **3. Definitions**

The term family support refers to, but is not limited to, those supports and services authorized under Title II of the Developmental Disabilities Act, Part C of IDEA, Titles V and XVI of the Social Security Act, and all other federal laws and all state laws that authorize services and supports for families of people with developmental disabilities or that authorize services and supports for people with developmental disabilities where the services and supports to people with disabilities, by statute or regulation, also include services and supports to their families.

### **4. Terminology**

The term “family supports and services” includes “interventions” that are intended to benefit families.

**B. Important Sources of National Goals**

1. *Troxel v. Granville*, 530 U.S. 57 (2000) and cases cited therein
2. Title II of the Developmental Disabilities Act
3. Part C of IDEA
4. Titles V and XVI of the Social Security Act

**C. How Does Current Knowledge Relate to National Goals?**

1. Research supports the conclusion that family-professional partnerships enhance outcomes for children and adults with disabilities and their families.
2. There is a limited but growing body of scientifically-sound research on effective policies, interventions, and financing mechanisms for enhancing family caregiving.
3. Research has confirmed that, despite recent efforts to increase the knowledge base regarding the unique needs and strengths of families from ethnically, culturally, and linguistically diverse backgrounds and of families who have non-traditional structures or members, these families are underrepresented in (a) intervention research, (b) needs assessment research, and (c) the development and utilization of policies, supports, and interventions.
4. There are many descriptive studies, but fewer scientifically-sound evaluative studies, on the utilization of various types of family supports and services, yet all of these studies confirm the growing availability and utility of those supports and services and their underlying policies.
5. There is scientifically-sound research on the prevalence and durability of family-based care across the lifespan of persons with developmental disabilities and on

the involvement of multiple family members in the care and support of their family members with developmental disabilities.

6. Although there are descriptive data on the structure and financing of state developmental disabilities systems, and more limited data on specialized family support initiatives, there is still an absence of systematic and broad-based understanding of the nature and extent of family supports and services already embedded in current state systems and of the role that different models of public financing systems play in these supports and services.
7. There is a substantial base of theoretical and methodological information about the economics of health care utilization and research. Policy-making entities should leverage these models in order to better understand the fiscal implications of shifting services towards family-oriented and family-directed service-delivery systems.

**D. How Can We Maintain, Improve, and Develop Research to Achieve our National Goals?**

1. We need to assert in all federal and state research-related and policy-making forums that families and the policies and practices that support their caregiving efforts are a legitimate focus of basic and applied policy, fiscal, intervention, and other research.
2. We need periodic national or sub-national assessments of family needs for supports and services so that the research community and the policy leadership at federal and state levels can ensure the relevance and utility of family support policies and services.

3. We must better articulate and operationalize the expected outcomes for supports and services for families, both for the purposes of program accountability and also for the development of cost-effectiveness and cost-benefit analyses of family support programs.
4. We need research and demonstration project evaluations that identify the desirability and means for converting traditional agency-based services to effective and flexible family-driven supports and services.
5. We need research on how exemplary practices that reflect family priorities and family-driven supports can be taken “to scale” in order to effect systems-change.
6. We need a greater effort and more resources to make promising model programs of family support widely available in all communities.
7. We need to identify, validate, disseminate, and use data on the outcomes of supports and services in order to ensure that federal and state policy are based on data (as well as on other salient factors).
8. We need to ensure that research-funding agencies encourage the use of multiple methodological approaches in research studies and encourage researchers to combine policy, fiscal, and/or intervention analyses and tool development activities, as appropriate to the research questions.
9. We need research on the effectiveness of family-professional and family-policymaker partnerships in developing policy, conducting research, and planning and using family supports and services.
10. Among these approaches must be those that are sometimes called Participatory Action Research but that include partnerships among researchers, family

members, practitioners, and policy-leaders in the design, execution, interpretation, and dissemination and utilization of research and demonstration data.

11. We need to identify effective strategies to enhance research, policy-making, and service-delivery partnerships with traditionally underserved and non-traditional families.
12. We must more precisely, and on the basis of research, articulate and operationalize the expected family outcomes across all domains of all family life, both for the purposes of program accountability and for the development of cost-effectiveness and cost-benefit analyses of family support policies and programs.
13. We need to encourage federal and state funding agencies to advance family support policy and practice, promote timely dissemination and utilization of research findings, and increase funding related to family support and services.
14. We need a larger body of scientifically sound research in order to evaluate the efficacy of family support policies and programs and to ensure that best practices are available to families and practitioners.
15. We need research that will identify and validate, for given family domain outcomes across families lifespan, new models of support and services that themselves are ecologically valid to ethnically and racially diverse families.

**E. How is Research Relevant to Self-Advocates, Families, Practitioners, and Policymakers?**

1. Research has helped to justify and shape the supports that now exist for families.
2. Research has demonstrated the durability of family care.

3. Research has shown its benefits for all of these audiences with respect to a wide range of issues, including without limitation parent-responsiveness training, behavioral parent training, positive behavior supports, cognitive-behavioral stress management education, parent-to-parent support, deinstitutionalization, respite care, cognitive coping, family enrichment, family therapy, family advocacy, person and family-centered action planning, and eco-behavioral interventions.

**F. How Can We Improve Sharing of Information to Achieve National Goals?**

1. We need to acknowledge that dissemination and utilization of research results are over-promised and under-funded activities, so we need assurances that funding for dissemination and utilization will accompany funding for research and demonstration activities.
2. We also need to acknowledge that no stakeholder group (e.g., researchers, practitioners, families, policy leaders, advocates) across the board has perceived that the dissemination and utilization of research is their responsibility. Accountability and role clarification for the dissemination and utilization of research is greatly needed.
3. We need ongoing partnerships with the recipients of research to ensure that relevant research is conducted and disseminated to all of them.
4. We need to ensure that research findings are accessible to and understandable by all audiences.
5. We need to support the translation of research findings into formats, language, and topics relevant to family members, practitioners, and policymakers.

**G. How Can We Improve the Link Between Current Knowledge and Public Policy?**

1. We should develop a standardized national and state database pertaining to the characteristics of the families served, the federal and state policies that relate to their caregiving and that support them, families' patterns of using services, and the effects of families' use of services on families and their members with developmental disabilities.
2. We need to develop the capacity to track—at the state level—the mix and flow of funding that is used to purchase family supports and services.
3. We should develop and disseminate scientifically sound, nationally and locally referenced means and tools for families and individuals to assess the benefits of federal and state policies and the performance of state and local service providers.
4. We need to disseminate to policymakers the research findings related to the cost-effectiveness and quality-of-life-enhancement outcomes of family-directed services.

**H. What Emerging Concepts May Affect Future National Goals?**

1. Federal research initiatives and federal disability-related policies and proclamations will explicitly acknowledge that families are legitimate beneficiaries of all kinds of developmental disabilities policies and services.
2. The shift to consumer and family control will present profound challenges to present systems of service-delivery, financing, and accountability.
3. Participatory action research, if supported by policymakers and researchers as well as by families and people with disabilities, will enrich the research

enterprise, increase the benefits of research to stakeholders, increase the amount of time that it requires to complete research, and add to its costs.

4. Evidence-based practice guidelines for family support will be identified and used as a matter of course by the research community and by research-funding agencies, and those guidelines will differ from the evidence-based practices and interventions that researchers use and that funding agencies expect in areas of developmental disabilities and service-delivery other than family support.
5. Family-centered practices across the lifespan will be identified and revised according to research findings.
6. Cultural brokers will be developed through community-based, family-directed and family-centered entities.
7. Parents with disabilities will be a focus of research, policy, and service initiatives.