

(2004) **Family quality of life.** *Beach Center Newsletter*. [NARIC Accession Number: O15700](#). Project Number: H133B031133. Abstract: Newsletter of the Beach Center on Disability. This issue focuses on family quality of life (QOL) for families of children with disabilities. Topics include: what is family QOL, what the law says about it, ways for teachers to address family QOL, international perspectives on families and people with mental retardation and QOL, the role of spirituality and religion, and tips for enhancing family QOL.

This document is available online at [naric.com](http://naric.com).

Blue-Banning, M. (2004) **Dimensions of family and professional partnerships: Constructive guidelines for collaboration.** *Exceptional Children*, 70(2), 167-184. [NARIC Accession Number: J47150](#). Project Number: H133B980050.

Abstract: Focus groups were conducted to explore the meaning of collaborative partnerships between families and professionals from the perspectives of parents of children with and without disabilities and service providers. In addition to the focus groups, 32 individual interviews were conducted with non-English-speaking parents and their service providers to ensure cultural and linguistic diversity. Indicators of professional behavior that facilitates collaborative partnerships were identified and organized into six themes: (1) communication, (2) commitment, (3) equality, (4) skills, (5) trust, and (6) respect. The specific meaning of each theme is described, including similarities and differences between professionals and family members. Implications for policy, practice, and future research are discussed.

Lazear, K. (2004) **System of care checklists. Family Experience of the Mental Health System.** [NARIC Accession Number: O16504](#). Project Number: H133B040024.

Abstract: Over a 2-year period, the Family Experience of the Mental Health System study systematically gathered information through interviews with 30 families as they sought services, experienced treatment, and discontinued services. Based on the experiences of the families in the study, as well as evidence-based and promising practices, these checklists can help guide the development of systems of care as they address child and family issues of: medication; decisions and responsibilities of care; pathways and access to care; and, helpfulness of formal organizations and informal supports.

This document is available online at [naric.com](http://naric.com).

Turnbull, Ann. (2004) **President's address 2004: "Wearing two hats": Morphed perspectives on family quality of life.** *Mental Retardation*, 42(5), 383-399. [NARIC Accession Number: J48196](#). Project Number: H133B980050.

Abstract: Current president of the American Association on Mental Retardation presents her own professional and family perspectives on ways to enhance family quality of life for families of children with developmental disabilities. The author provides an overview of the five domains of family quality of life: disability-related support, physical/material well-being, emotional well-being, parenting, and family interaction. She illustrates each domain with examples from her own family experiences and shares insights and next steps that families and professionals can take for addressing priority issues.

Walker, J(Ed.). (2004) **Focal point: Partnering with families, 18(1).** [NARIC Accession Number: O15493](#). Project Number: H133B990025.

Abstract: Issue focuses on family/professional partnerships within systems of care serving children with emotional or behavioral disorders. Topics covered include: disclosure and reciprocity, collaboration between early childhood program directors and mental health professionals, promoting inclusion in child care centers, team practices to increase individualization in wraparound, partnership in evaluation, and family participation in out-of-home treatment settings.

This document is available online at [www rtc.pdx.edu/pgFPS04TOC.php](http://www rtc.pdx.edu/pgFPS04TOC.php)

## NIDRR Grantees on the Cutting Edge

**National Resource Center for Parents with Disabilities**, *Through the Looking Glass* (H133A040001) led by Paul Preston, PhD. Phillip Beatty, Project Officer.

Abstract: The National Resource Center for Parents with Disabilities focuses on the 10.9 percent of U.S. families with children in which one or both parents have a disability—nearly 9 million parents. The Center provides: (1) accessible and disability-appropriate information regarding parenting with a disability to parents, potential parents, disability advocates, and legal, medical, and social service providers; (2) training to parents with disabilities, potential parents, and service providers; (3) technical assistance that increases informed practice and informed decisions; (4) program consultation that increases local and regional services that are accessible and disability-appropriate. To accomplish these goals, project researchers: (1) consolidate and disseminate information and resources, (2) synthesize and disseminate materials from other agencies and organizations, (3) develop and disseminate new materials tailored to address the specific needs of parenting with disabilities and service providers, (4) expand the national availability of training and technical assistance to parents with disabilities and service providers, and (5) develop curricula to train future service providers. Parenting areas designated as highest priority are: custody, pregnancy and birthing, adoption, adaptive parenting equipment, and general parenting information. The project is staffed by nationally recognized experts regarding parents with disabilities, the majority of whom are parents with disabilities or family members of parents with disabilities.

Find out more at: [www.lookingglass.org](http://www.lookingglass.org)

**Rehabilitation Research and Training Center on Policies Affecting Families of Children with Disabilities**, *University of Kansas* (H133B031133) led by H.R. Turnbull, LL.M.; Ann Turnbull, EdD. Bonnie Gracer, Project Officer.

Abstract: This center conducts eight research projects on the effects of the policies of governments, systems, networks, and agencies on the family quality of life and community integration (FQOL/FCI) of families who have children with developmental disabilities and emotional-behavioral disabilities or both. Researchers identify four target populations: families, providers, policy-leaders, and networks (all at the federal, state, and local levels). Two policy challenges are prisms through which the effects of policies on families can be understood: early intervention and consumer control of funding. For each policy challenge, researchers inquire into whether the applicable federal and state policies and practices, and the applicable network policies, advance FQOL/FCI; whether the policies across education, social services, and health care are mutually consistent with each other and advance FQOL/FCI; and whether the practices of agencies in those systems advance FQOL/FCI. The center's analytical framework holds that the core concepts shape policies, policies shape

### A Family Portrait

In the US, 20.9 million families have one or more members, 5 years or older, with a disability. 2.8 million families are raising a child with a disability. That works out to 1 in 26 US families.

Source: *Census 2000*.

Please note: These abstracts have been modified. Full, unedited abstracts, as well as any available REHABDATA citations, are available at [naric.com](http://naric.com).

Thousands of additional resources on these topics are available from NARIC's resource pages at [www.naric.com/public](http://www.naric.com/public)

services, policies and services should be coordinated and delivered through partnerships. Enhanced FQOL/FCI occurs when there is coherence among core concepts, coordinated policies delivered through partnerships, and coordinated services delivered through partnerships; and influencing factors must invariably be taken into account. Find out more at: [www.beachcenter.org](http://www.beachcenter.org)

**Rehabilitation Research and Training Center for Community Integration for Individuals with Disabilities, Strengthening Family and Youth Participation in Child and Adolescent Mental Health Services, Portland State University (H133B040038)** led by Barbara Friesen, PhD, Bonnie Gracer, Project Officer.

Abstract: This project conducts research, training, and technical assistance activities to study and promote effective, community-based, culturally competent, family-centered, individualized, and strength-based services for children and youth with emotional or behavioral disorders and their families. Projects include: (1) "Community Integration (CI) of Transition-Age Youth," designed to gain understanding of CI and related concepts from the perspectives of transition-age youth, young adults, and caregivers; (2) "Transforming Futures: Research on Expanding the Career Aspirations of Youth with Mental and Emotional Disorders," explores transition experiences; (3) "Partnerships in Individualized Planning" develops an intervention to increase youth and family member participation in the individualized service planning process, a conceptual framework for understanding recovery in children's mental health, and ways to reduce stigma; (4) "Work-Life Integration" addresses CI for adult caregivers of children and youth with emotional disorders, specifically around maintaining employment. It is designed to influence human resource professionals' practice, and aims to reduce stigma and increase organizations' family friendliness; (5) "Transforming Transitions to Kindergarten" focuses on the preschool-kindergarten transition for young children with challenging behaviors. It develops and tests an intervention promoting children's successful school entry while empowering caregivers; (6) "Practice-Based Evidence: Building Effectiveness from the Ground Up," conducts a case study in partnership with a Native American youth organization and the National Indian Child Welfare Association, and addresses the need to study practices that are believed to be helpful, but for which little evidence exists.

Find out more at: [www.rtc.pdx.edu](http://www.rtc.pdx.edu)

**Development of Measures of Participation and Environment for Children with Disabilities, Boston University (H133G070140)** led by Wendy J. Coster, PhD, Dawn Carlson, PhD, MPH, Project Officer.

Abstract: This project develops new measures of participation and environment for children and youth with disabilities using input from families and their children with disabilities. The new measures are developed using Item Response Theory (IRT) to ensure that the measures developed are interpretable, provide interval level data for analyses, and are valid for the specified purposes. The project has three major phases. The first phase is a development phase that synthesizes results from prior research on participation and environment and analysis of the ICF with information derived from focus groups of caregivers and children and youth with a variety of disabilities to identify meaningful domains and item content areas for the new measures. Initial item pools are developed, subjected to expert review and cognitive testing, and then field-tested with both caregiver and child respondents to identify any significant problems with scaling or content coverage using IRT methods. After revisions based on these results, a larger field study is conducted using both paper and web-based survey formats to examine the properties of the revised item pools. The ultimate aim is to develop large pools of participation and environment items that can support survey and computer-adaptive testing measures that are linked on a common scale.



Photo Credit: Felix Atsoram, Argentina

The Beach Center's Family Quality of Life Conversation Guide is available to download, free of charge, from their website at [www.beachcenter.org](http://www.beachcenter.org). Families and professionals can use this guide to think through their needs for support services, Individualized Family Service or Education Plans, community groups, and other resources.

#### Where Can I Find More?

A quick keyword search is all you need to connect to a wealth of disability and rehabilitation research. NARIC's databases hold more than 75,000 resources. Visit [www.naric.com/research](http://www.naric.com/research) to search for literature, current and past research projects, and organizations and agencies in the US and abroad.



ERIC, the Education Resources Information Center, maintains one of the most comprehensive databases of literature on education research. It includes more than 115,000 full text articles. Browsing through the Thesaurus, we clicked Individualized Family Service Plans and found 181 abstracts with 101 full text documents. Try your own search at [eric.ed.gov](http://eric.ed.gov).

## Current Literature - Selections from REHABDATA

Olkin, R., Abrams, K. (2006) **Comparison of parents with and without disabilities raising teens: Information from the NHIS and two national surveys.** *Rehabilitation Psychology, 51(1)*, 43-49. [NARIC Accession Number: J50251](#). Project Number: H133B30076; H133G990130.

Abstract: Study compared parents with disabilities who are raising children ages 11 to 17 years with families headed by parents without disabilities. Data from three sources were examined: (1) the National Health Institute Survey (NHIS), (2) a previous survey of parents with disabilities, and (3) a new national survey of parents with disabilities. Parents with and without disabilities completed a survey designed for this study. Overall, parents with disabilities were generally quite similar to parents without disabilities. The similarities and differences are presented in five categories: (1) income and employment, (2) teen household responsibilities, (3) positive characteristics attributed to teens by parents, (4) barriers experienced by parents with disabilities, and (5) differences across particular disability types.

Rizzolo, M., Hemp, R. (2006) **Family support services in the United States. Policy Research Brief, 17(1).** [NARIC Accession Number: O16653](#). Project Number: H133B031116.

Abstract: This brief provides an overview of family support services based on data gathered for the State of the States in Developmental Disabilities Project, a longitudinal study of public financial and program trends in intellectual or developmental disabilities. Family support for families of children with disabilities consists of a range of services such as direct cash payments to families, vouchers, reimbursement, or direct payments to service providers that help families keep their children at home. Information is provided on the types and levels of family support spending and the number of families supported in each state and the District of Columbia. This document is available online at [naric.com](http://naric.com).

Gordon, L., Tullis, K. (2005) **Building on family strengths: Research and services in support of children and their families: 2004 conference proceedings.** [NARIC Accession Number: O16366](#). Project Number: H133B990025.

Abstract: Publication presents proceedings from the annual conference of the Research and Training Center on Family Support and Children's Mental Health, which focuses on improving services to families whose children have mental, emotional, or behavioral disorders. Transcripts from the keynote and plenary sessions, as well as summaries of paper, symposium, and poster presentations are provided. The conference agenda and an index of authors are included. This document is available online at [naric.com](http://naric.com).

(2004) **Disability policy and accountability.** *Beach Center Newsletter.* [NARIC Accession Number: O15668](#). Project Number: H133B031133.

Abstract: Newsletter of the Beach Center on Disability. This issue focuses on disability policy and the concept of accountability for families of children with disabilities. Topics include: (1) the story of Marilyn Arons, teacher, advocate, and parent; (2) tips on how parents and professionals can avoid disagreements over what's best for the child; (3) a checklist for parents on steps to follow to resolve disputes with service providers; (4) information on the Council of Parent Attorneys and Advocates, an organization that helps parents, advocates, and others acquire educational services for children with disabilities; and (5) a book review, project news, and resources. This document is available online at [naric.com](http://naric.com).