

Research Highlights

Topic: Family Quality of Life

Turnbull, A.P., & Turnbull, H.R. (2002). From the old to the new paradigm of disability and families: Research to enhance family quality of life outcomes. In J.L. Paul, C.D. Lavelly, A Cranston-Gingras, & E.L. Taylor (Eds.), *Rethinking professional issues in special education* (pp. 83-119). Westport, CT: Ablex Publishing.

BOTTOM LINE

This book chapter traces the history of family research over the past century and then focus on two elements of a new paradigm: a family-centered model of research and a family empowerment/family quality of life model.

TIPS

- Research associated with a state-of-art quality enhancement process should focus on increasing.
 - ◆ The incorporation of disability core concepts into services,
 - ◆ Infusing an empowering process into the family-service provider, intra-agency, and interagency partnerships
 - ◆ Increasing family quality of life outcomes.
- Family research must have empowerment and quality of life as the outcomes for families, including members with disabilities.
- Support the evolving self-determination of the child or youth with a disability by ensuring power-through support rather than power-over.

KEY FINDINGS

- In earlier paradigms, professionals were “experts” and parents were “cases,” “clients,” “patients,” and/or “trainees.”
- Historically, professionals maintained a “power over” relationship with parents in which they tried to “fix” children with disabilities and/or their mothers.

KEY FINDINGS

cont.

- The almost sole focus of special education has been to “fix” the student’s development deficits, with little attention to self-determination of students and/or their parents.
- IDEA’s authorized equal-decision making between professionals and parents resulted primarily in power-over relationships between professionals and mothers.
- A power-over approach is especially problematic for families from culturally and linguistically diverse backgrounds and activist parents who want to be empowered decision-makers.
- The family-centered model, introduced in the 1980s, has three central characteristics: family choice, family strengths perspective, and family as the unit of support.
- The family empowerment/family quality of life model emphasizes empowerment as the **process** and family quality of life as the outcome of research and professional services.
- In this new paradigm, the major shift is in “fixing” the multiple environments in which the family desires authentic participation from “fixing” the child and parents.
- There also is an increased emphasis on family-centered services and research characterized by family choice, a family strengths perspective, and the family as the unit of support.
- A participatory action research approach is consistent with the new paradigm research model emphasizing family empowerment/family quality of life.

RELATED PUBLICATIONS

- Brown, R.I., Brown, P.M., & Bayer, M.B. (1994). A quality of life model: New challenges arising from a six-year study. In D.A. Goode (Ed.), *Quality of life for persons with disabilities: International perspectives and issues* (pp. 39-56). Cambridge, MA: Brookline Books.
- Park, J., Hoffman, L., Marquis, J., Turnbull, A.P., Poston, D., Mannan, H., Wang, M., & Lord-Nelson, L. (2003). Toward assessing family outcomes of service delivery: Validation of a family quality of life survey. *Journal of Intellectual Disability Research*, 47, 367-384.

RELATED
PUBLICATIONS

- Park, J., Turnbull, A.P., & Turnbull, H.R. (2002). Impacts of poverty on quality of life in families of children with disabilities. *Exceptional Children*, 68(2), 151-170.
- Poston, D., Turnbull, A., Park, J., Mannan, H., Marquis, J., & Wang, M. (2003). Family Quality of life: A qualitative inquiry. *Mental Retardation*, 41(3), 313-328.
- Wang, M., Mannan, H., Poston, D., Turnbull, A.P., & Summers, J.A. Parents' perceptions of advocacy activities and their impact on family quality of life. *Research and Practice for Persons with Severe Disabilities*, 29(2), 144-155.

For more information, contact the Beach Center on Disability at 1200 Sunnyside Avenue, 3111 Haworth Hall, the University of Kansas, Lawrence, KS 66045-7534. Phone: 785-864-7600. Email: Beachcenter@ku.edu. Website: www.beachcenter.org.

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