Classic & Foundational Works in Supporting People with IDD and Their Families

Rights, Self-Determination & Quality of Life

The Foundational Era: From Institutions to Community (1960s–1970s)

Nirje, B. (1969). "The Normalization Principle and Its Human Management Implications." In Kugel & Wolfensberger (Eds.), Changing Patterns in Residential Services for the Mentally Retarded. President's Committee on Mental Retardation.

> **Why it matters:** Bengt Nirje articulated the normalization principle — that people with intellectual disabilities have the right to patterns and conditions of everyday life that are as close as possible to the norms of mainstream society. This was the philosophical cornerstone of deinstitutionalization and the community inclusion movement.

Wolfensberger, W. (1972). The Principle of Normalization in Human Services. National Institute on Mental Retardation, Toronto.

> **Why it matters:** Wolfensberger expanded normalization into a comprehensive framework for evaluating and redesigning human services. His later concept of Social Role Valorization (1983) deepened this — arguing that enhancing the social roles and perceived value of people with disabilities is the core mission of services.

Blatt, B., & Kaplan, F. (1974). Christmas in Purgatory: A Photographic Essay on Mental Retardation. Human Policy Press.

> **Why it matters:** A photographic exposé of institutional conditions that made the moral case for deinstitutionalization more powerfully than any academic article. Widely credited with galvanizing public opinion, parent advocacy, and landmark court decisions in the 1970s.

Self-Determination: A Right, Not a Privilege (1990s–2000s)

Wehmeyer, M. L. (1992). "Self-Determination and the Education of Students with Mental Retardation." Education and Training in Mental Retardation, 27, 302–314.

> **Why it matters:** The article that launched the modern self-determination movement in disability services and special education. Wehmeyer defined self-determination as acting as the primary causal agent in one's own life — making choices free from undue external influence. This reframed the goal of supports from compliance and caregiving to empowerment and autonomy.

Wehmeyer, M. L. (1998). "Self-Determination and Individuals with Significant Disabilities: Examining Meanings and Misinterpretations." Research and Practice for Persons with Severe Disabilities, 23(1), 5–16.

> **Why it matters:** Critically challenged the assumption that people with significant cognitive disabilities cannot be self-determined. This article extended the concept to people across

the full spectrum of disability, arguing that self-determination is about causal agency and autonomy — not cognitive capacity.

Quality of Life: A Framework for Personal Outcomes (1990s–2010s)

Schalock, R. L. (Ed.). (1996). Quality of Life, Volume I: Conceptualization and Measurement. AAIDD.

Why it matters: This landmark volume established quality of life (QOL) as the central organizing concept for disability supports and services. Schalock's model identified eight core domains — emotional well-being, interpersonal relationships, personal development, physical well-being, self-determination, social inclusion, material well-being, and rights — providing a framework that now drives person-centered planning worldwide.

Schalock, R. L., & Verdugo, M. A. (2002). Handbook on Quality of Life for Human Service Practitioners. AAIDD.

Why it matters: Translated the QOL framework into practical guidance for practitioners and organizations. It became the international reference for designing, implementing, and evaluating supports based on what matters most to the person — not what is easiest for systems to provide.

Schalock, R. L., et al. (2002). "Conceptualization, Measurement, and Application of Quality of Life for Persons with Intellectual Disabilities." Mental Retardation, 40(6), 457–470.

Why it matters: An international consensus paper by leading scholars that established QOL as a measurable, multidimensional construct applicable across cultures and service systems. Among the most-cited articles in the IDD field.

The Supports Paradigm: Redefining Disability (2000s–2010s)

AAIDD (Luckasson et al., 2002; Schalock et al., 2010). Intellectual Disability: Definition, Classification, and Systems of Supports (10th & 11th editions). AAIDD.

Why it matters: These editions of the AAIDD manual fundamentally shifted the definition of intellectual disability — away from a fixed deficit in the person toward a functional description of the mismatch between a person's capacities and their environment. The 2010 edition formalized the supports paradigm: identifying the pattern and intensity of supports a person needs is more useful than classifying severity by IQ.

Thompson, J. R., et al. (2009). "Conceptualizing Supports and the Support Needs of People with Intellectual Disability." Intellectual and Developmental Disabilities, 47(2), 135–146.

Why it matters: Provided the conceptual foundation for the Supports Intensity Scale (SIS), one of the most widely used tools for IDD planning. This article articulated why measuring what supports a person needs — rather than cataloguing deficits — is the correct starting point for individualized planning and resource allocation.

Person-Centered Planning & Community Inclusion

O'Brien, J. (1987). "A Guide to Life-Style Planning." In Wilcox & Bellamy (Eds.), A Comprehensive Guide to the Activities Catalog. Paul H. Brookes.

Why it matters: John O'Brien's work introduced and popularized person-centered planning approaches — including MAPS, PATH, and Essential Lifestyle Planning — that start from the person's vision for their own life rather than available slots in a service system. These tools transformed how teams and families plan with (not for) people with IDD.

Mount, B. (1994). "Benefits and Limitations of Personal Futures Planning." In Bradley, Ashbaugh & Blaney (Eds.), Creating Individual Supports for People with Developmental Disabilities. Paul H. Brookes.

Why it matters: Beth Mount's Personal Futures Planning framework centered on the person's gifts, relationships, and preferred future — a radical departure from deficit-focused service planning. This work is the direct ancestor of today's person-centered thinking tools used throughout the IDD field.

Disability Rights, Policy & Inclusion

Americans with Disabilities Act (ADA), 1990. U.S. Public Law 101-336.

Why it matters: Not an article, but the landmark federal law that established disability as a protected civil rights category and prohibits discrimination in employment, public services, and accommodations. For people with IDD, the ADA fundamentally expanded the legal basis for community inclusion and anti-discrimination protections.

Olmstead v. L.C., 527 U.S. 581 (1999). U.S. Supreme Court.

Why it matters: The Supreme Court ruling that unjustified institutionalization of people with disabilities violates the ADA. Olmstead established the legal mandate for community-based services and has driven state-level HCBS expansion for more than two decades — one of the most important legal decisions in the history of IDD services.

Families — Supports, Strengths & Partnership

Understanding the Family Experience (1960s–1980s)

Olshansky, S. (1962). "Chronic Sorrow: A Response to Having a Mentally Defective Child." Social Casework, 43, 190–193.

Why it matters: The first influential article on the emotional experience of families. Olshansky introduced "chronic sorrow" — an ongoing, recurrent grief that does not resolve over time, distinct from acute mourning — to describe the lived experience of parents. It fundamentally changed how professionals approached family emotional support and is still cited today.

Turnbull, A. P., & Turnbull, H. R. (1986). Families, Professionals, and Exceptionality. Merrill/Prentice Hall. (Subsequent editions through the 2010s.)

Why it matters: The defining text on family-professional collaboration. It introduced family systems theory as the framework for understanding how disability affects the entire family — not just the individual. The framework addresses family characteristics, interactions, functions, and life cycle stages, recognizing that culture, socioeconomic status, family size, and the nature of disability all shape family experience.

The Enabling and Empowering Framework (1980s–1990s)

Dunst, C. J., Trivette, C. M., & Deal, A. G. (1988). Enabling and Empowering Families: Principles and Guidelines for Practice. Brookline Books.

Why it matters: One of the most-cited works in the family support literature. It introduced the "enabling and empowering" framework — the idea that professionals should build family capacity and mobilize both formal and informal support networks, rather than delivering services to passive recipients. Its influence on early intervention practice is enormous and enduring.

Singer, G., & Irvin, L. (Eds.). (1989). Support for Caregiving Families: Enabling Positive Adaptation to Disability. Paul H. Brookes.

Why it matters: A seminal edited volume synthesizing research on family stress, coping, and support needs. It bridged research findings with practical guidance for professionals working alongside families and established the evidence base for family support services.

Family Quality of Life (2000s–2010s)

Turnbull, A. P., Brown, I., & Turnbull, H. R. (Eds.). (2004). Families and People with Mental Retardation and Quality of Life: International Perspectives. AAIDD.

Why it matters: This volume operationalized family quality of life (FQOL) as a measurable construct — shifting the field's attention from deficits and stress toward what families themselves define as a good life. It sparked an international wave of FQOL research and shaped how services are evaluated from the family's perspective.

Kyzar, K. B., Turnbull, A. P., Summers, J. A., & Gómez, V. A. (2012). "The Relationship of Family Support to Family Outcomes: A Synthesis of Key Findings." Research and Practice for Persons with Severe Disabilities, 37(1), 31–44.

Why it matters: A landmark review synthesizing two decades of literature (1990–2010) on the relationship between family support and family outcomes — including family functioning, satisfaction, quality of life, and stress — for families of children with moderate to severe disabilities. It documented the field's shift from a deficit to a support model.

National Agenda for Family Support

Hecht, M., et al. (2011). Building a National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities. (Wingspread Conference Report.) Johnson Foundation.

Why it matters: This seminal policy report defined the overarching goal: to maximize families' capacity, strengths, and unique abilities so they can best support, nurture, and facilitate self-determination, interdependence, productivity, and inclusion for their family members with IDD. It became a guiding framework for federal policy and practice.

Diversity, Equity & Intersectionality in Family Support (Current Frontier)

Grossman, B., & Magaña, S. (2016). "Introduction to the Special Issue: Family Support of Persons with Disabilities Across the Life Course." Journal of Family Social Work, 19(1–2).

> **Why it matters:** Presented an ecological and life course framework for understanding family caregiving — recognizing that family members are a primary, often unpaid, source of support from early childhood through aging. It identified critical gaps in research at each life stage and called for more inclusive study designs.

Magaña, S., and colleagues. (2024). "A Research Agenda to Support Families of People with IDD with Intersectional Identities." Intellectual and Developmental Disabilities (AAIDD).

> **Why it matters:** Represents the current frontier. This AAIDD paper calls for research centering families with intersectional identities — including Black, Indigenous, Latine, immigrant, and LGBTQ+ families — and argues that person-centered, family-centered, and culturally relevant approaches are essential for supporting all families across the lifespan. It also importantly expands the definition of family to include chosen families.

Key journals: Intellectual and Developmental Disabilities (AAIDD) • American Journal on Intellectual and Developmental Disabilities (AJIDD) • Research and Practice for Persons with Severe Disabilities (RPSD) • Journal of Policy and Practice in Intellectual Disabilities (JPPID). For current research, see aaidd.org.