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From The Old to The New Paradigm of Disability and Families: Research to Enhance Family Quality of Life Outcomes

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The new paradigm of disability is contextual and societal: A person has an impairment that becomes a disability as a result of the interaction between the individual and the natural, built, cultural, and social environments. Accordingly, research into the natural, cultural, and social environments is warranted and is targeted at enhancing enablement and preventing disablement.

We take as a fact that one of the natural environments affecting individuals with disabilities is their family. A person with a disability affects and is affected by the person's family; families are systems in which an event that affects primarily one person (e.g., a child with a disability) also affects all other members (Turnbull & Turnbull, 2001; Whitechurch & Constantine, 1993). The converse is true, as well (particularly as it concerns families who have children with disabilities): Whatever happens to the family affects the child as well. A leading family therapist describes the reverberating impact of family members on each other analogous to a mobile:

In a mobile all the pieces, no matter what size or shape, can be grouped together and balanced by shortening or lengthening the strings attached or rearranging the distance between the pieces. So it is with the family. None of the family member is identical to any others; they are all different and at different levels of growth. As in a mobile, you can't arrange one without thinking of the other. (Satir, 1972, p. 119-120)

It follows, then, that family research is wholly consistent with the new paradigm.

Upon this fact we rest certain assertions. These are as follows:

1. Families are integral to society.
2. Their empowerment and quality of life are the sine qua non of research on families.
3. Whatever research is conducted on and on behalf of families should have the consequence of advancing the empowerment and quality of life of the individual with a disability.
4. Research on, and on behalf of the individual (especially when the individual is a child—defined as a person who is legally a minor), should also benefit the family's empowerment and quality of life.

In this paper, we trace the history of family research over the past half-century. We show how it was premised originally on a psychotherapy model; how it moved from that model to a parent training model; and then how it left that model for a parent involvement model. We argue

that these three models together constitute an old paradigm of research on, and on behalf of, families.

We then focus on the two elements of the new paradigm. These are a family-centered model of research and a family empowerment/family quality of life model. In a nutshell, we assert that the new paradigm must involve family research and that the only type of family research that is tolerable under the new paradigm is that which has empowerment and quality of life as the outcomes for families, including members with disabilities. We suggest a research program and teacher education program consistent with this new paradigm vision.

The Old Paradigm of Disability and Families

The old paradigm characterizes disability as a deficit within the individual resulting in functional impairments associated with daily activities. Thus, the old paradigm service system primarily focuses on “fixing” the individual’s functional impairments as contrasted to providing environmental accommodations.

Just as the old paradigm influences individuals with disabilities, so it also influences families of children and youth with disabilities. Three examples of the old paradigm’s service and research models targeted on families include (a) the psychotherapy model, (b) the parent training model, and (c) the parent involvement model (Turnbull, Turbiville, & Turnbull, 2000). We now analyze these three old paradigm models.

Psychotherapy Model

The psychotherapy model, most prevalent in the 1950s-1960s, regarded the birth of a child with a disability as a “tragic crisis” that could best be dealt with by providing psychotherapy to the child’s parents in order to help them overcome their grief and cope with the unexpected and presumptively unwanted fact of disability (Bowlby, 1960; Goshen, 1963; Mandelbaum & Wheeler, 1967; Solnit & Stark, 1961; Wolfensberger, 1967). In the case of some disabilities, such as autism and asthma, parents were considered to be the cause of their child’s disability (Akerley, 1985; Warren, 1985; Gallagher, 1985). Accordingly, psychoanalysis was aimed at “fixing” the parents so that they, in turn, could “fix” their child. This view is described by Ruth Sullivan, a parent of a son with autism, who experienced the brunt of this old paradigm.

Parents who were not around in the 1950s, 60s, and even 70s trying to get a diagnosis for their (usually) beautiful young child with extremely difficult and inexplicable behavior might have a hard time understanding the oppressive and guilt-provoking dogma of most mental health professionals at that time. For some parents that I knew then, each time they took their child for an evaluation, they were told that they (especially the mother) had caused the autism. Families who could afford it went into psychotherapy or psychoanalysis. No assistance was given to the parents in handling the day-to-day worrisome behavior of their child. The theory, acted upon as fact, was that once the parents recognized and confronted their repressed and deep-seated anger (which caused their child to withdraw) they would then be fit to raise their otherwise normal child.

Bruno Bettelheim, the most articulate proponent of this mindset, was a skillful and much published writer...In Bettelheim’s book, The Empty Fortress, he compares the homes of autistic children to Nazi concentration camps (where, as an Austrian Jew, he was once a prisoner). (Turnbull, Turnbull, Shank, & Leal, 1999, p. 413)

In the psychotherapy model, parents frequently became the “cases” to receive “treatment” from the “experts” who had the decision-making power to define “normalcy.” The “treatment” was to “fix” mothers’ personal pathologies so that they could be an adequate parent of their child. Almost no attention was given to changing or supporting the family’s environment, enabling it to build on the family’s or child’s strengths and to address needs so as to best support the child’s development and self-determination and the family’s integrity and wholeness.

The psychotherapy model reflects a *power-over* relationship (see Table 1) in which professionals exerted decision-making control over parents through their socially awarded higher status, their trained competence, and their insistence on having control of outcomes of their relationships with families and the child. Professionals possessed the power to “diagnose” and to prescribe “treatment” which, if not followed, would suggest that the parents were “dysfunctional”. Figure 1 summarizes key elements of the psychotherapy model.

Although the psychotherapy model was particularly prevalent in the 1950s-1960s, there are still applications of it today. It probably is more prevalent in the area of emotional disability than in other types of disability professional-family interaction.

Parent Training Model

Beginning in the 1970s and proceeding to the 1980s, the primary emphasis shifted from psychotherapy to parent training. Largely influenced by President Johnson’s Great Society Programs and the emergence of the Head Start model (Hunt, 1972; Zigler & Valentine, 1979), the parent training model also presumed parental deficits. It suggested that parents needed to be “fixed” by expanding their knowledge and skills. The assumption was that knowledge and skill needed to be provided by professionals to families in a unidirectional fashion, with almost no recognition being given to the value of parents sharing their knowledge and skills with other parents (Turnbull, Blue-Banning, Turbiville, & Park, 1999).

With Head Start as the precursor, Congress authorized the 1968 Handicapped Children’s Early Education Program for children birth to eight. The program’s major goal was to enhance the development of preschoolers with disabilities (“fix” their functional impairments) (Harvey, 1977). A major strategy for developmental gain was enlisting parents as early intervention allies, as the Chairman of the Select Committee on Education, Congressman Dominick V. Daniels, made clear:

Few parents are prepared to take care of a child who looks different, behaves in grossly unacceptable ways or fails to respond even to the sound of a mother’s voice. Parents of handicapped children have fears and are often frustrated and bewildered. They need help in understanding their child’s disability. They need help in working with their handicapped child.

This bill will bring us into a new era of educating handicapped children. In addition, it is anticipated that this legislation will enlist the help of the parents as allies and associates of educators to provide a total program. (Lavor & Krivit, 1969, p. 381)

Table 1
 Overview of Old and New Paradigm of Disability and Families

Service/Research Emphasis	Type of Power	Type of Decision-Making	Participants	Anticipated Outcome
Parent psychotherapy; parent training; parent involvement	Power-over 	Exerting control	Professionals and mothers	“Fixing” deficits of mothers as conduit of “fixing” child
Family-centered services	Power-with 	Collaborating	Families and professionals	Addressing families’ priorities
Family empowerment/ family quality of life	Power-through 	Synergizing	Families, friends, community citizens, and professionals	Strengthening empowerment; enhancing family quality of life

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21-year-old son with a developmental disability, describes the impact of the parent training model on her relationship with her son.

The message to me as a mother that was pervasive in early intervention's emphasis on developmental milestones was that we needed to "fix" James. The harder I worked, the more he would achieve. And achievement was the name of the game. "Developmental milestones"—how I learned to hate those words. They were the gold medals for the winners of the "fix it" set.

I readily became James' teacher. His playtime at home became "learning time"—actually all his time was learning time. Any free time we had was to be spent on his therapy or to be spent feeling guilty that we weren't doing his therapy. I remember one developmental milestone that he never achieved—stacking three blocks. He had finally achieved stacking two blocks; the next milestone was stacking three. I modeled for him, prompted him, and finally held his hand while we did it together. Inevitably, when left to attempt it on his own, James would pick up the blocks and throw them. He found this hysterically funny. His early intervention teacher thought he was noncompliant. James obviously didn't get the fact that his ticket to acceptance rested heavily on stacking those blocks (Turnbull, Blue-Banning, Turbiville, & Park, 1999, p. 165).

Parent Involvement Model

The parent involvement model received a major impetus when IDEA was first implemented in 1975. IDEA specified active roles for parents in educational decision-making. The most prominent and frequent role is involvement in the IEP conference. Over 20 years later, parent involvement is still primarily actualized in elementary, middle, and secondary schools by parents attending IEP conferences. Although the IEP process was intended to provide a context for *equal* decision-making among parents and professionals, the *power-over* approach (see Table 1) has clearly been prevalent. Extensive reviews of research on parent involvement in IEP conferences reveals that schools try to comply with the (letter but not the spirit) of legal mandates; however, there is scant evidence that the IEP process has empowering outcomes for students, parents, or educators (Smith, 1990; Turnbull & Turnbull, in press). Interestingly, almost no research has focused on the outcomes of the IEP process, but rather research has addressed issues such as teacher, parent, and student roles, topics discussed at meetings, the length of meetings, and the content addressed (Espin, Denot, & Albayrak-Kaymak, 1998; Farel, Shackelford, & Hurth, 1997; Gerber, Banbury, Miller, & Griffin, 1986; Getzel & deFur, 1997; Goldstein & Turnbull, 1982; Lewis, Busch, Proger, & Juska, 1981; Lynch & Stein, 1982; Nadler & Shore, 1980; Pyecha, Cox, Dewitt, Drummond, Jaffe, Kalt, Lane, & Pelosi, 1980; Salembier & Furney, 1998; Smith & Simpson, 1989).

Moreover, parent involvement in educational-decision making has occurred primarily through the involvement of mothers (Able-Boone, 1993; Campbell, Strickland, & La Forme, 1992; Turnbull & Turnbull, in press). Only limited attention has been given to the involvement of children and youth with disabilities and other family members (Morningstar, Turnbull, & Turnbull, 1995; Shellady, Hendrickson, Reisen, Sampson, & Vance, 1994; Van Reusen & Bos, 1994). Parent reports clearly document limited decision-making influence in IEP conferences, mediation, and due process hearings (National Council on Disability, 1995; Turnbull & Turnbull, in press).

A *power-over* approach associated with parent involvement in educational decision-making is particularly problematic for families from culturally and linguistically diverse

backgrounds (Harry & Kalyanpur, 1999; Kalyanpur & Harry, 1999). Researchers have described a conflict of culture between the bureaucratic special education culture, operationalized through IDEA, and the culture of families from culturally and linguistically diverse backgrounds that relies more on relationships rather than legal procedures:

The combination of the “direct,” informal manner of American professionals, with their assumptions of the validity of detached, scientific information (Wright et al., 1983), can be alienating rather than reassuring for people accustomed to a slower pace, more personal yet more generalized approach....The bureaucratic structure of schools, and, certainly of the special education system, with its formal procedures and systems, presents people from such cultures with a formidable challenge. When these systems are implemented without regard for the need for personalized information, and, as has been emphasized earlier, without opportunity for dialogue, the result is often confusion and alienation on the part of parents and increasing impatience on the part of professionals. When they are implemented in a vein of compliance rather than communication the results can be disastrous (Harry, 1992b). (Harry & Kalyanpur, 1994, p. 160)

A second group of parents who have been particularly frustrated by the *power-over* approach of the parent involvement model are activist parents who have a strong empowerment orientation. The perspectives of many of these parents were set out in the National Council on Disability hearings on IDEA conducted in 1994. The Council’s reports is replete with testimony characterizing the high level of frustration experienced by families who have attempted to be empowered decision-makers (National Council on Disability, 1995):

I have come to call myself Bonnie, the bitch, because of what I’ve had to become to fight the system for the handicapped child, and yet I have contacted multiple state offices. I have followed through with every lead that anybody has ever given me. I have talked with the Governor’s office here in the state. I’ve gone so far as to call the White House....I guess my feeling at this point is, “Is there anybody out there who really cares?” I don’t know what more to do. I, as a parent, have pursued every option. (testimony by Bonnie Weninger, in National Council on Disability, 1996, p. 123)

When you have to advocate for your child, you pay a high price for that in many ways. It’s very stressful on the family....Because of the kind of advocacy work that I’ve had to do...I’m not able to teach anywhere locally. I actually teach school in Texas, which is a 30-mile drive in the time difference away from my home....My son suffers from bipolar disorder and numerous other difficulties. That illness itself is stressful, but when you have a vindictive, harassing, retaliatory school district to deal with, it makes your life completely miserable...that’s what I’ve had to deal with. (Edris Klucher, Albuquerque, NM) (National Council on Disability, 1995, p. 124)

Summary

Key themes characterizing the old paradigm of services and research related to families of children and youth with disabilities include the following:

1. Children with disabilities and their mothers were viewed as needing to be “fixed”. (We limit this comment to children with disabilities because there is almost no emphasis in old

paradigm literature about youth with disabilities. Likewise, there is almost no emphasis on any family members other than mothers.)

2. “Fixing” the mothers was viewed as a conduit for “fixing” the child.
3. Professionals were “experts” and parents were “cases”, “clients”, “patients”, and/or “trainees”.
4. IDEA’s authorized equal-decision making between professionals and parents resulted primarily in *power-over* relationships between professionals and mothers.
5. The almost sole focus of special education has been to “fix” the student’s developmental deficits, with little attention to self-determination of students and/or their parents.
6. Negligible attention was given to any environmental accommodations.
7. The literature is absent of any descriptions related to outcomes from service-delivery or research such as family empowerment and/or enhancement of family quality of life.

NEW PARADIGM OF DISABILITY AND FAMILIES

Family services and research has been in transition from the old to the new paradigm. One of the bridges between the old and new paradigm has been an emphasis on family-centered services and research. Once that bridge is crossed, the emerging model for family research emphasizes a family empowerment/family quality of life model (Turnbull & Turnbull, 2001; Turnbull, Turbiville, & Turnbull, 2000).

Family-Centered Model

The family-centered model was introduced in the 1980s in early intervention and early childhood services and research. The family-centered model has many definitions; but among these many definitions, there are three central characteristics—family choice, family strengths perspective, and family as the unit of support (Allen & Petr, 1996).

First, the family-centered model primarily attempted to honor family choice by changing the power relationship between professionals and families, moving from a *power-over* approach to a *power-with* approach (see Table 1). A major emphasis is encouraging families to take the lead in stating their priorities and having professionals respond to those priorities (Dunst, Johnson, Trivette, & Hamby, 1991; McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1993; Turnbull, Turbiville, & Turnbull, in press).

Second, the family-centered model abandoned a pathology orientation and adopted a strengths orientation (Bailey & McWilliam, 1993; Dunst, Trivette, & Deal, 1988; Saleebey, 1996). This approach is evident in IDEA, Part C, which requires the identification of family priorities, resources, and concerns as part of the process to develop the individual family services plan (this legislation uses the term, resources, rather than strengths).

Third, the entire family is the unit of support, not just the child with a disability and the child’s mother. An outgrowth of this approach has been an emphasis on conducting research and providing support to fathers (Ainge, Colvin, & Baker, 1998; Byson, 1997; Frey, Fewell, & Vadasy, 1989; Meyer, 1995; Levine, Murphy, & Wilson, 1993), siblings (Heller, Gallagher, & Fredrick, 1999; McHale & Gamble, 1989; Meyer & Vadasy, 1994; Powell & Gallagher, 1993; Stoneman & Berman, 1993), and extended family (Able-Boone, Sandall, Stevens, & Frederick, 1992; Meyer & Vadasy, 1986; Mirfin-Veitch, Bray, & Watson, 1996, 1997). It is disconcerting

that the family member who is most neglected in family research is the individual with the disability.

Currently, the family-centered model is considered the prevalent one in early intervention and early childhood services for young children with disabilities (McWilliam, Lang, Vandiviere, Angel, Collins, & Underdown, 1995; Murphy, Lee, Turnbull, & Turbiville, 1995; Wehman, 1998). Research indicates, however, that the family-centered philosophy is stronger than its actual implementation (Katz & Scarpati, 1995; McBride, Patterson, Joanning, Whiddlen, & Demmit, 1993; Menke, 1991).

At the elementary, middle, and secondary school levels, the bridge from the old to the new paradigm is not as strong as it is during the early years. The emphasis is still much more on parent involvement in IEP conferences and parent attendance at school events than on a family-centered model and on a shift in the power relationship from a *power-over* to a *power-with* orientation (Turnbull & Turnbull, 2001).

Family Empowerment/Family Quality of Life Model

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. This model emphasizes a participatory action research approach as part of the new paradigm.

Family quality of life as outcome. Within all human service areas, there is a contemporary emphasis on conceptualizing and measuring outcomes. As stated by Schorr (1997):

A new attention to results [outcomes] signals a profound shift, because it moves us from the technocratic concerns with procedural protections to focus on the purpose of what we choose to pursue. If we as a nation are serious about efforts to strengthen children, families, and depleted neighborhoods, we must know the outcomes we are after and we must be continually able to monitor progress—and face up to failures as well (p. 116).

There appears to be general agreement that a positive family quality of life should be an appropriate outcome of policies and services (Bailey, et al., 1998; Osher, 1998; The Accreditation Council, 1995; Turnbull & Brunk, 1997; Turnbull, Blue-Banning, Turbiville, & Park, 1999; Turnbull, et al., in press). Research in conceptualizing and measuring the quality of life of individuals with disabilities has far exceeded comparable work focusing on the family quality of life (Brown, Brown, & Bayer, 1994; Cummins, 1997; Felce & Perry, 1997; Gardner, Nudler, & Chapman, 1997; Keith, Heal, & Schalock, 1996; Schalock, 1997). The research literature has not yet conceptualized and developed a taxonomy and corresponding measurement system for family quality of life domains and indicators; however, a research agenda for such work is described in this chapter.

Empowerment as process. Although definitions of empowerment vary across disciplines, the central definitional element of empowerment is taking action to get what one wants and needs (Akey, Marquis, & Ross, in press; Benett, DeLuca & Allen, 1996; Cochran, 1992; Dempsey, 1996; Dunst, Trivette, & LaPoint, 1992; Gutiérrez & Nurius, 1994; Heflinger, Bickman, Northrup, & Sonnichsen, 1997; Koren, DeChillo, & Friesen, 1992; Man, 1998, 1999; Pinderhughs, 1994; Rappaport, 1987; Turnbull, Turbiville, & Turnbull, 2000; Turnbull & Turnbull, 2001).

The type of power characterizing an empowering process is a *power-through* approach (see Table 1) in which synergy is created leading to the collective empowerment of all participants (Bond & Keys, 1993; 1974; Katz, 1984; Senge, 1990). Synergy is a combustible catalyst for collective empowerment of all partners as they collaborate to make environmental accommodations.

Key components of an empowering process are (a) participation of key stakeholders and (b) commitment to changing community ecology to enable families to enhance their quality of life. In terms of participation, all family members are key decision-makers in terms of sharing visions, preferences, and preferred modes for problem-solving. An empowering process strongly encourages self-determination of children and youth with disabilities, from the earliest ages, in developing motivation and knowledge/skills to direct their own lives (Turnbull & Turnbull, 2001; Wehmeyer, Agran, & Hughes, 1998; Wehmeyer & Sands, 1998). Thus, a critically important element for family roles is to support the evolving self-determination of the child or youth with a disability in ensuring *power-through* support rather than *power-over* parental and/or professional control.

The emphasis on changing the community ecology is a pervading theme of an empowerment process. Figure 1 illustrates five environmental levels that is patterned after Bronfenbrenner's (1979) model of ecological systems as they apply to families of children and youth with disabilities. The shaded portion of the family level includes the child with the disability and parents. This is the portion that the old paradigm emphasizes—"fixing" the parents so that they can, in turn, "fix" the child. Alternatively, the new paradigm, as characterized in the family empowerment/family quality of life model, emphasizes the entire environment in terms of what accommodations are needed (through an empowerment change process) so that the family can experience the quality of life that is important to them as depicted in Figure 2. The family empowerment/family quality of life process that permeates this approach is characterized as follows:

- regarding the child as an authentic member of the family's and community's ecological environments,
- taking stock of what is important for the family in terms of quality of life *across all five systems*,
- determining what is in place that is consistent with family priorities,
- determining what accommodations are needed to create a better match between what is important and what exists in the family members' lives, and
- providing supports and services to all key stakeholders to create preferred quality of life enhancements.

In this new paradigm, the major shift is in "fixing" the multiple environments in which the family desires authentic participation, rather than "fixing" the child and parents. Thus, the emphasis is on *transformed* services, communities, societies, and cultures within which families, including children and youth with disabilities, can flourish in their development as they interact with responsive contexts (Turnbull, Blue-Banning, Turbiville, & Park, 1999).

Participatory action research. Participatory action research refers to research that is conducted jointly by families and researchers as they collaboratively set the research agenda, implement it, and assure that the fruits of knowledge derived from the research are disseminated to families, administrators, service providers, and policymakers (Turnbull, Friesen, & Ramirez, 1998).

and, (d) families and researchers should be in a “*power through*” relationship. Figure 3 illustrates a continuum of family participation in research. Levels 4-6 in Figure 3 constitutes the nature of partnerships that are necessary for participatory action research.

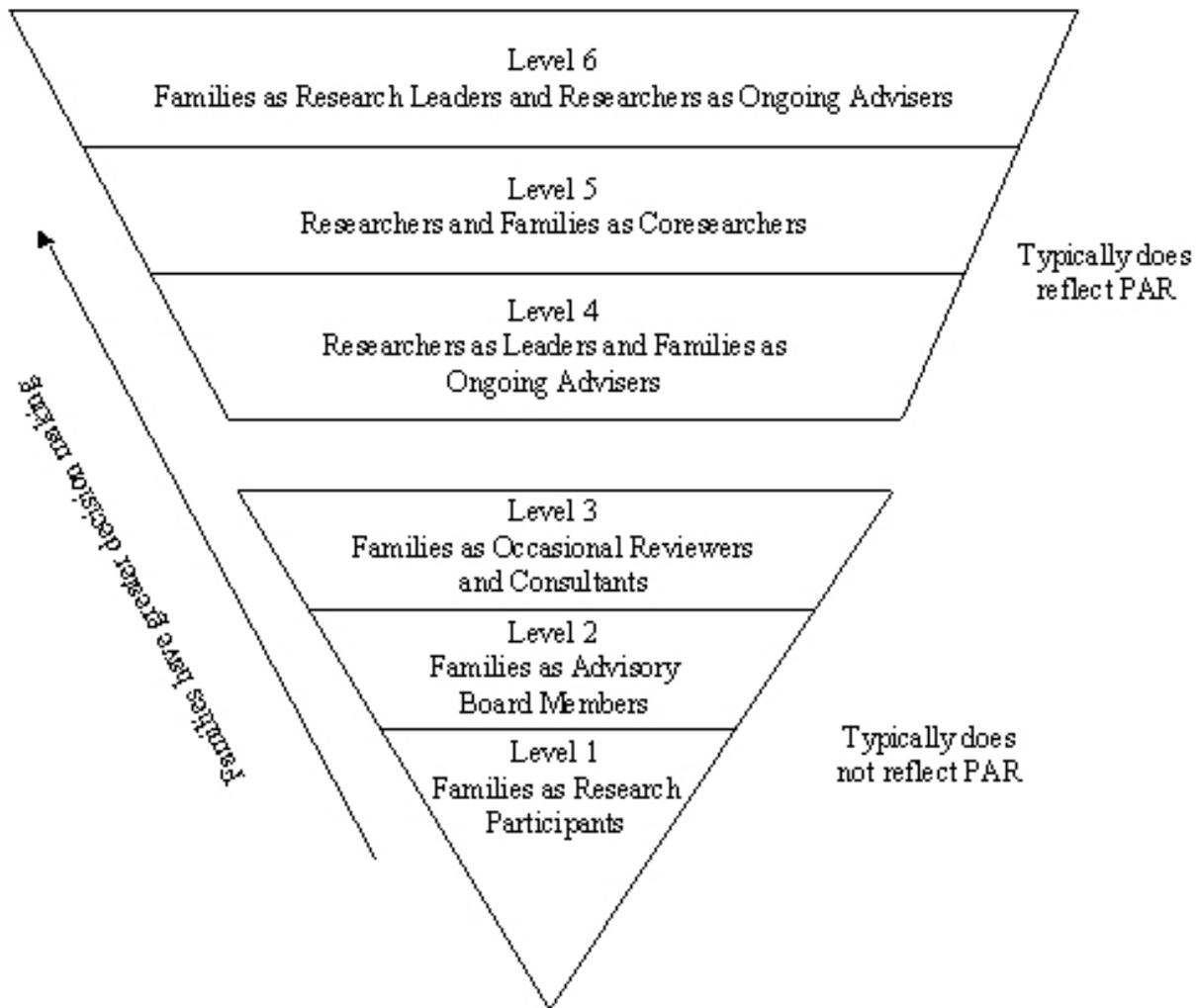


Figure 5-3. Continuum of family participation in research. *From:* Turnbull, A.P., Friesen, B.J., & Ramirez, C. (1998). Participatory action research as a model for conducting family research. *Journal for the Association for Persons with Severe Handicaps*, 23(3), 178-88.

Summary of New Paradigm

Key themes characterizing the new paradigm of services and research related to families of children and youth with disabilities include the following:

1. Particularly at the early childhood level there is an increased emphasis on family-centered services and research characterized by family choice, a family strengths perspective, and family as the unit of support.
2. A family-centered model has served as a bridge between the old and new paradigm.
3. A family empowerment/family quality of life model exemplifies the new paradigm of disability and family. The key theme is “fixing” the broad environment (from macro to micro levels) so that all of society, including families of children and youth with disabilities, take action to ensure quality of life outcomes.
4. A transformed ecology is necessary in order to enhance family quality of life outcomes.
5. A participatory action research approach is consistent with the new paradigm research model emphasizing family empowerment/family quality of life.

NEW PARADIGM ANALYTICAL FRAMEWORK FOR ENHANCING FAMILY QUALITY OF LIFE

Building on the foundation of understanding the evolution from the old paradigm to the new paradigm related to disability and families, we now turn our attention to an analytical framework aimed at illuminating the connections between policy, services, and family quality of life outcomes. Figure 4 is an analytical framework that is currently guiding our new paradigm family research at the Beach Center. This analytical framework has four major components. In this section we will describe those components and relate them to key literature. The four components are (a) core concepts, (b) policy, (c) services, and (d) family quality of life outcomes.

The first component of the analytical framework is the core concepts of disability policy. These core concepts reflect fundamental values—values that advance the quality of life for citizens with disabilities and their families, values that are widely recognized as necessary for the pursuit of life, liberty, and happiness (Brakel, Parry, & Weiner, 1985; Levy & Rubenstein, 1996; Minow, 1990; Silverstein, 1998; Turnbull, 1990). Relating back to Figures 1 and 2 depicting the five environmental levels, core concepts of disability and family policy occur at the culture level and pervasively influence not only the policy level but the other three levels as well. Table 2 includes the core concepts of disability policy as they have currently been identified by our Beach Center policy research. The process of identification has been (a) a systematic review of federal statutes and case law and (b) focus groups of nationally recognized family advocacy organization leaders, policy leaders at the federal/state levels and senior policy and family researchers in the disability field.

The second component of the analytical framework is public policy. The disability policy core concepts should be infused into policy and services at federal, state, and local levels (vertical implementation). Disability policy core concepts should also be infused *across* the strands of education, human and social services, and health care (horizontal implementation.)

The third component of the analytical framework is service delivery. Within the delineation of environmental levels (Figures 1 and 2), services at the state and local levels are typically at the services and community levels. In addition to the usual emphasis on the *vertical coherence* of policies and services, we are especially interested in *horizontal coherence* that leads to systems of care and service integration (Adelman & Taylor, 1997; Burns & Goldman, 1999; Calfee, Wittwer & Meredith, 1998; Dryfoos, 1997, 1998; Sailor, in press; Stroul, 1996). We believe a service integration approach characterized by empowering partnerships at the family-professional, intra-agency, and interagency levels will particularly benefit families, especially those who face multiple challenges.

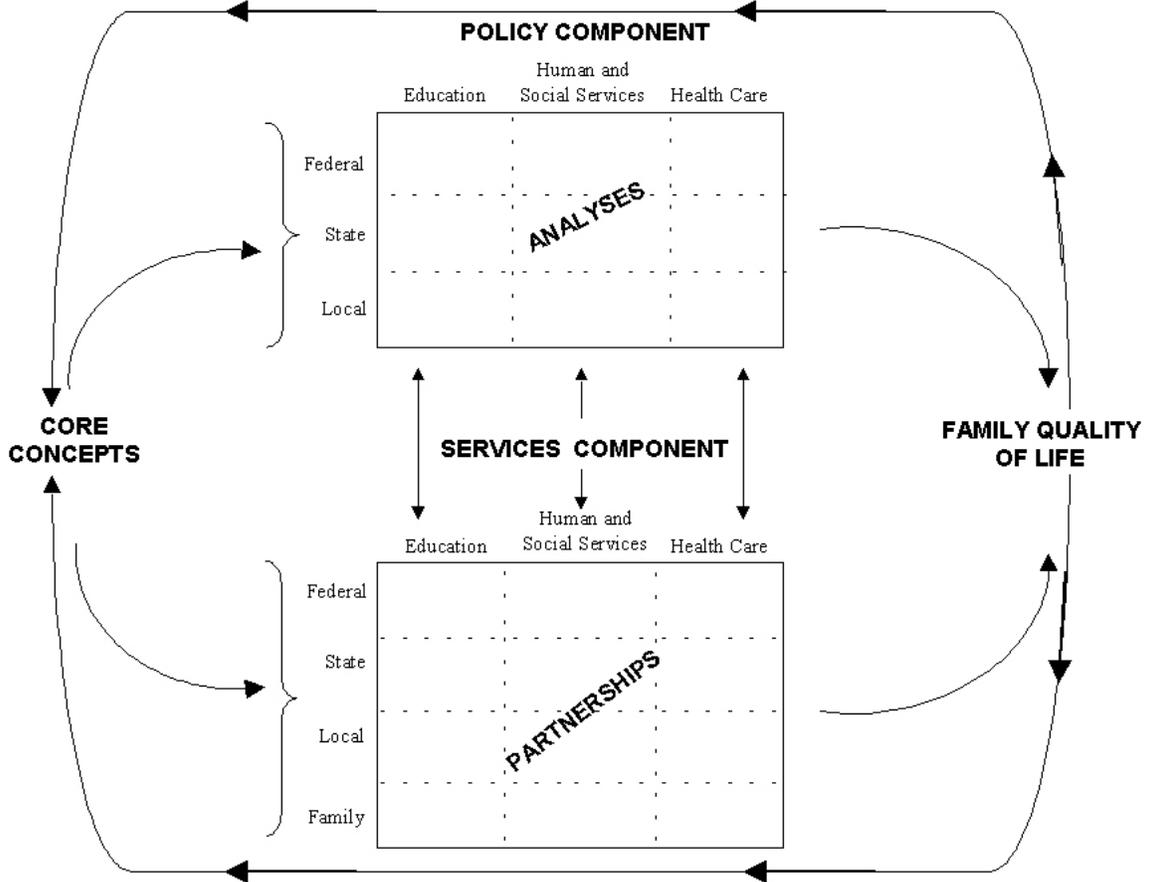


Figure 5-4. New paradigm analytical framework for enhancing family quality of life.

Table 5-2
Definitions of Core Concepts

Anti-discrimination	Under various statutes generally known as “civil rights acts,” it is illegal to discriminate against a person with a disability solely by reason of the person’s disability.
Autonomy	This term refers to the right of a person with a disability or the person’s family to consent, refuse to consent, withdraw consent, or otherwise control or exercise choice or control over what happens to him or her.
Empowerment/ Participatory Decision-Making	Empowerment involves the means by which a person or family or their duly appointed surrogate secure what they want from a service provider system; the means is through their participation with the system in consenting

	(see “autonomy”) or otherwise participating in the decision making processes by which the services that they will receive are planned, developed, implemented, and evaluated.
Privacy and Confidentiality	Privacy refers to protection against unwarranted governmental interference in decision making that affects private interests.
Liberty	A person has the right to be free from unwarranted physical or other confinement by a government.
Protection against Harm	A person has the right to be free from harm while in state custody or in the care of such private individuals as family members or other caregivers.
Individualized & Appropriate Services	These services are specially tailored to meet the needs and choices of persons with disabilities and their families.
Capacity-Based Services	Capacity-based services evaluate the unique strengths and needs of a person with a disability or the person’s family.
Classification	Classification includes processes (ways) and the standards (criteria) by which a person with a disability or the person’s family qualifies (becomes eligible) to benefit from certain laws (anti-discrimination or other rights or entitlements).
Productivity and Contribution	Productivity refers to engagement in income-producing work or in other unpaid work that contributes to a household or community.
Integration	A person with a disability has the right to not be segregated, solely on the basis of disability, from persons who do not have disabilities and to not be barred from participation in services that serve persons who do not have disabilities or to be limited to participation in services that serve only persons with disabilities.
Family Integrity and Unity	Policy presumes in favor of preserving and strengthening the family as the core unit of society.
Family-Centeredness: Services to Whole Family	These services respond to the needs of the entire family of a person with a disability in an individualized and appropriate manner.
Service Coordination & Collaboration	These activities assist individuals with disabilities or their families to access and benefit from services from more than one provider system (inter-agency) or within a

	single provider system (intra-agency).
Cultural Responsiveness	These services respond to the beliefs, values, interpersonal styles, attitudes, cultural, ethnic, linguistic, or other socioeconomic traits of the person or family and thereby have a great likelihood of ensuring maximum participation of and benefit to the person or family.
Accountability	This term refers to various methods of achieving the specified outcomes of services.
Prevention	Prevention services seek primary, secondary, and tertiary prevention of disability.
Professional Capacity	A service system should have the capacity to implement any one or more concepts, as appropriate for that system.

In terms of multiple challenges, family demographic research has identified economic status and family structure as two critically important variables that must be addressed in new paradigm research. These services must be delivered through empowering partnerships at the family-service level, intra-agency level, and interagency level. Regarding economic status, children whose families have low income are 1.4 times more likely than children from other families to have chronic health conditions; they are 1.9 times more likely to have limitations in major activities; and they are 2 times more likely to be completely unable to carry out a major activity for their age (LaPlante & Carlson, 1999; Fujiura & Yamaki, 1997; Newacheck & Halfon, 1998). Regarding family structure, single parenthood is a significant predictor of poverty (Fujiura & Yamki, 1997; Sherman, 1994; U.S. Census Bureau, 1996). In 1996, 59% of children under six who lived in female-household families were living below the poverty line (Forum on Child and Family Studies, 1998).

Many families who live with complex and multiple challenges, including those associated with economic status and family structure, have needs not only within the vertical strands of education, human and social services, and health care, but also across horizontal strands. Paradoxically, the service system typically responds to horizontal problems by crafting vertical semi-solutions (Toffler, 1990). Policies and systems deal with only segments of families in children's lives; a comprehensive, integrated service delivery approach to families and children is elusive. Families need policies and service systems characterized by intra-strand and inter-strand partnerships and service integration.

The fourth component of our analytical framework is family quality of life, which we have previously discussed. The theory of change leading to enhanced family quality of life outcomes inherent in this analytical framework is as follows:

1. Core concepts should shape policy (statutes, regulations, and court cases) (a) at the federal, state, and local levels and (b) across the three strands of education, social services, and health care;
2. Policy shapes service delivery structures and processes (a) at the federal, state, local, governmental, and at the family levels, and (b) across the three strands of education, human and social services, and health care;

3. Enhanced family quality of life results when policies and services are (a) infused with the core concepts and (b) delivered through partnerships;
4. Family quality of life domains/indicators should influence and be integral to core concepts, so that, in turn, the core concepts' impact on policies and services will advance and enhance family quality of life;
5. Accordingly, there should be an unbroken loop in the relationship among (a) core concepts, (b) policies, (c) services, and (d) family quality of life outcomes.

RESEARCH DIRECTIONS EMANATING FROM NEW PARADIGM ANALYTICAL FRAMEWORK

This analytical framework (see Figure 4) generates a comprehensive, long-term research program whose ultimate aim is to enhance family quality of life. We will describe research directions in terms of (a) development of measurement tools and (b) an overview of a programmatic research agenda (see <http://www.beachcenter.org>).

Development of Measurement Tools

The new paradigm analytical framework requires new measurement tools. Three of these measurement tools include the following:

1. A disability policy core concepts matrix for policy analysis is needed to assess specific statutes/regulations regarding core concepts.
2. A family quality of life scale is needed to assess the outcomes of policies and services on families. In order to develop such a measure, a starting point is the development of a taxonomy of family quality of life domains and indicators. Figure 5 outlines the sequential process of combining qualitative and quantitative research methods to ensure that the family quality of life scale is grounded in the perspectives of families while simultaneously possessing rigorous psychometric properties.
3. Partnership scales are needed to measure partnerships in delivering services at the levels of family-service provider, intra-agency, and interagency. These scales will measure the third component of the analytical framework. They, too, require the combination of qualitative and quantitative methodologies depicted in Figure 5.

Overview of Programmatic Research Agenda

These measurement tools will be used to accomplish research agenda focusing on three levels: (a) policy analysis, (b) explanatory research, and (c) program evaluation and quality enhancement.

Policy analysis. Policy analysis research is needed to analyze federal and state statutes and their respective regulations to determine the degree to which they incorporate one or more of the disability policy core concepts and family quality of life domains (see Table 2). Two levels of analysis are needed: (a) the extent to which it is *appropriate* for statutes/regulations to reflect specific disability policy core concepts and family quality of life domains, and (b) the extent to

which statutes/regulations reflect *coherence* with disability policy core concepts and family quality of life domains.

Because statutes have different purposes, it is not *appropriate* for every disability policy core concept to be incorporated into every statute/regulation. For example, it arguably is more *appropriate* for IDEA to reflect the disability policy core concept of productivity than it is for the Developmental Disabilities Assistance and Bill of Rights Act to do so. This is so because IDEA has the explicit affirmative purpose of providing an appropriate education so the student will secure employment after leaving school. By contrast, the DD Act creates state wide, systems-change opportunities, only some of which are related to productivity. Thus, a first task for policy analysis is to establish a reliable rating of *appropriateness*.

An analysis is also needed of the extent to which statutes/regulations are *coherent* with respect to core concepts and family quality of life domains. *Coherence* addresses the consistency with which the statute and regulations incorporate the disability core concepts and family quality of life domains throughout all of its parts.

Based on policy analysis, it will be possible to develop a “Disability Policy Grade Card” for key statutes/regulations to communicate to interested stakeholders the extent to which policy advances the disability policy core concepts. More importantly, the policy analysis research can serve as a basis for policy enhancement through (a) the legislative route (e.g., amendments to existing statutes and enactment of new laws), and/or (b) the executive agency route (e.g., amendments to existing regulations, promulgation of new regulations; adoption of guidelines governing the content of competitive contracts, grants, and cooperative agreements). Technical assistance priority should be given to working on statutes/regulations that are deemed to be highly *appropriate* for incorporation of disability core concepts but currently have low *coherence*.

For many years, family-and-disability research has seemed to be unconnected to research involving families whose children do not have disabilities. The practice of separate-but-equal research agendas—one for families and disability, another for families and non-disability—has at least two significant limitations. One limitation is that many families who have children with disabilities also have children who do not have disabilities; their concerns, so far as research and its dissemination and utilization are concerned, are therefore about not just disability but also about family policy generally. A second limitation is that a disability-only approach fosters the segregation that many families and individuals with disabilities find anathema and which federal policy condemns.

Fortunately, the new paradigm recognizes that families affected by disability, just like individuals affected by disability, are nested within and are strongly influenced by and strongly influence policy, practice, and research as they affect all families. Accordingly, the new paradigm calls for merging two separate lines of research—the line that is disability only and the line that is not-at-all disability. At the Beach Center, this merger—this honoring of the new paradigm—is underway as we conduct research on the core concepts of disability policy and link that research to our work on the core concepts of family policy. Moreover, this merger is also underway as we include families whose children do not have disabilities into our research on family quality of life.

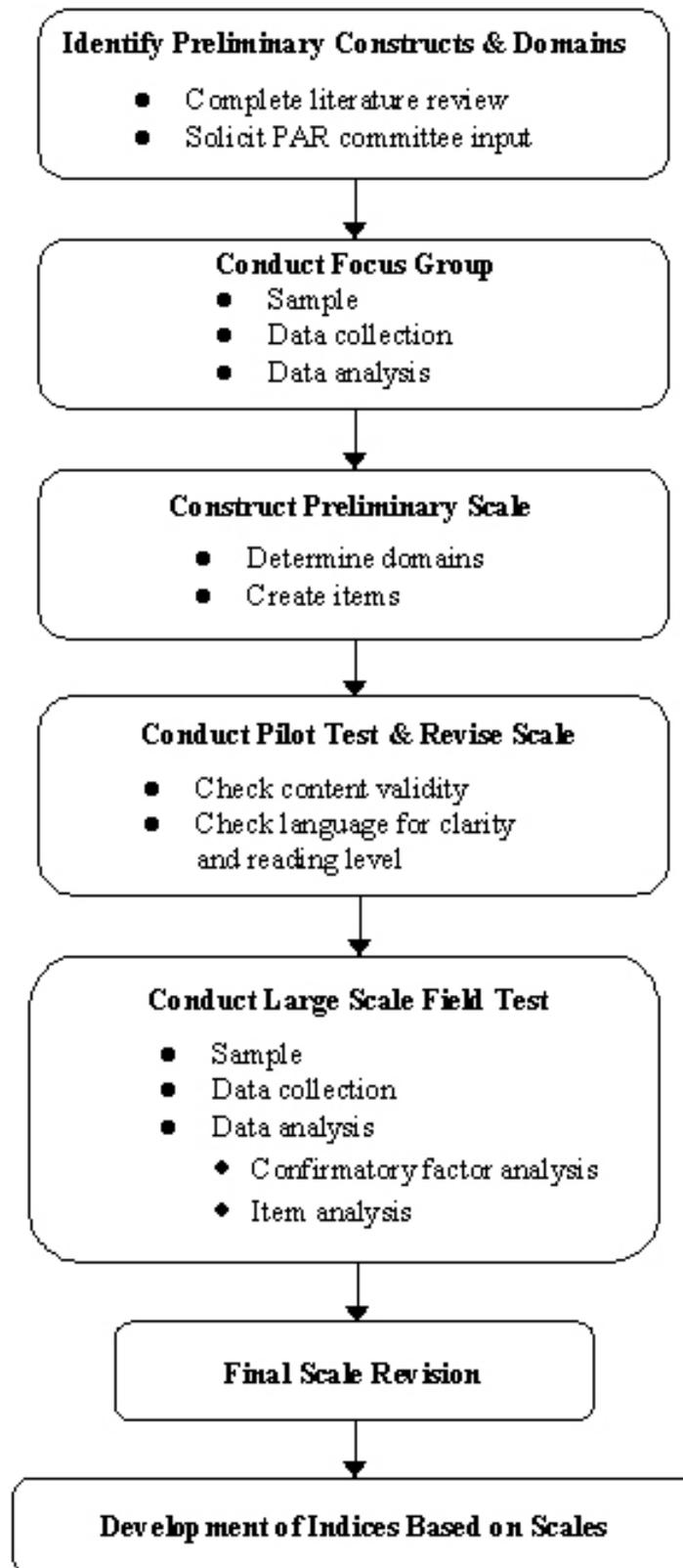


Figure 5-5. Steps in constructing family quality-of-life and partnership scales.

The underlying premise—one that can hardly be disputed, no matter what policy perspectives one may have about families and given the new paradigm—is that families are, and for more than a decade have been, legitimate foci of NIDRR research and of the new paradigm.

Explanatory research. There is a need for research to examine statistically the relationship between the core concepts of disability policy, service provision offered through partnership arrangements, and family quality of life outcomes. Based on the analytical framework, a structural model can be hypothesized that (a) a family's perceived quality of life is positively related to the services the family receives and that (b) the processes through which the services are delivered (incorporation of core concepts based on authorizing policies and empowering partnerships at the family-service provider, intra-agency, and interagency levels) will mediate the relationship between the services and the family quality of life. This structural model can be tested separately for each of the three service strands of education, human and social services, and health. It can also be tested in programs that are explicitly aimed at service integration. Figure 6 is a structural model that is based on the analytical framework.

In addition to investigating the mediating facts of this structural model, the relationship among the various factors can also be investigated in light of the family's structure, cultural and linguistic diversity characteristics, and socioeconomic level. As we stated earlier, these are the variables that have been found to place families of children with disabilities at highest risk.

An explanatory research strand of research is particularly important in adding to the state-of-art knowledge base given that policy and service variables impacting family quality of life have not been systematically investigated previously. Furthermore, this research will provide a framework for quality enhancement to improve outcomes for families in a variety of service settings.

Program evaluation and quality enhancement. In order for policy analysis and explanatory research to benefit families (including children and youth with disabilities), the third stage in the research process is conducting thorough program evaluation and quality enhancement processes within strand-specific programs, as well as programs reflecting state-of-art service integration. The Council on Quality and Leadership in Supports for People with Disabilities (The Council) has taken a leadership role in combining principles of total quality management, re-engineering, and disability state-of-art concepts (Gardner & Nudler, 1999). Their process has focused on personal outcomes for adults with developmental disabilities; an extension of this work is needed to focus on outcomes for families of children and youth with disabilities. Special emphasis is needed on the needs of families who are most at risk, including families with single-parent status and lower socioeconomic income.

Research associated with a state-of-art quality enhancement process should focus on increasing (a) the incorporation of disability core concepts into services, (b) infusing an empowering process into the family-service provider, intra-agency, and interagency partnerships, and (c) ultimately increasing family quality of life outcomes. A research methodology appropriate for this type of program evaluation and quality enhancement research is a multiple case study design that allows for the analysis of individual cases as sub-units as well as cross case analyses designed to identify patterns (Yin, 1994). Thus, case study methodology fits within the core of these scientific method as a valuable means for exploring the impact and process related to quality enhancement (Campbell, 1994). Table 3 outlines possible phases of a quality enhancement process that incorporates case study data as a guide to technical assistance and training.

TEACHER EDUCATION DIRECTIONS EMANATING FROM NEW PARADIGM ANALYTICAL FRAMEWORK

The analytical framework (see Figure 4) and the comprehensive, long-term research program that we have just described have major implications for teacher education. We see that we have a responsibility to translate theory and research into teacher education preservice and inservice instructional materials. The way that we have approached that responsibility is to prepare a textbook that is entitled *Families, Professionals, and Exceptionality: Collaborating for Empowerment* (4th edition) (Turnbull & Turnbull, 2001). This book is published by Merrill/Prentice Hall; outlines of the chapters can be found on their website (<http://www.prenhall.com/turnbull/>). The book is currently in its 4th edition; and as we complete research based on the new paradigm approach, we will continue to prepare new editions to incorporate this research so that the textbook will reflect the latest and best knowledge that we have. We will briefly describe this textbook in terms of its organization and key features.

**Table 5-3
Quality Enhancement Process**

1. A quality enhancement team comprised of individuals with disabilities, parents, service providers, and community representatives administer measurement tools to administrators, services providers, and families in the service agency.
2. The quality enhancement team presents the results of the measurement process to all stakeholder groups.
3. The quality enhancement team facilitates the service agency staff in an agency analysis. Each family quality of life domain is examined from a perspective of the agency's mission, task, process, structure, and personnel.
4. The quality enhancement team, working with agency stakeholders, develops a quality enhancement plan for agency. The quality enhancement team analyzes the linkages between and among the various organizational systems to ensure all systems are aligned to promote outcomes.
5. The quality enhancement team and agency staff, in collaboration with agency stakeholders, implement the quality enhancement plan.
6. The quality enhancement team re-administers the measurement tools on a periodic basis to monitor progress and refine the agency enhancement plan.

Text Organization

Families, Professionals, and Exceptionality is organized into three parts:

1. Part I: "Understanding Empowerment"—This section describes the concept of empowerment historically and currently.
2. Part two: "Understanding Families"—This part describes families as interactive systems and enables students to understand the unique and idiosyncratic characteristics of families and how they relate to the families' perspectives on what constitutes quality of life for them.

3. Part three: “Collaborating for Empowerment”—This portion explains how professionals and families can collaborate to take action to address seven opportunities for partnerships. These seven opportunities for partnerships include:

- Communicating among reliable allies,
- Meeting families’ basic needs,
- Referring an evaluating for special education,
- Individualizing for appropriate education,
- Extending learning into home and community,
- Attending and volunteering at school, and
- Advocating for systems improvement.

We emphasize that *what* families and professionals do in their partnerships, such as the previous seven opportunities for partnerships, is a very important part of the empowerment equation but it is not all of it. It is equally important in *how* they carry out these activities. We describe partnerships as reliable alliances and we underscore the necessity of infusing the following eight obligations for reliable alliances into every partnership:

- Knowing yourself
- Knowing families
- Honoring cultural diversity
- Affirming family strengths
- Promoting family choices
- Envisioning great expectations
- Communicating positively
- Warranting trust and respect

We place emphasis on how teams can create reliable alliances (a) to identify barriers that are standing in the way of quality of life and (b) to move forward in decisively removing those barriers to enhance family quality of life.

Text Features

In seeking to be consistent with a family-centered approach, we have put families at the center of the book by starting each of the 15 chapters with a vignette about a real family who is experiencing real challenges in real communities. These family vignettes are told as family stories; and we believe that they enrich, inform, and enliven the research and best practice information that is found throughout the book. In fact, we believe that part of the new paradigm is to bring together the very best of firsthand, anecdotal, qualitative insight about families with current research and best practice findings. We reject the notion that information has to be dichotomized in “one camp” (quantitative research) or the “other camp” (family stories) in terms of how knowledge is verified. We seek the best of all worlds in merging knowledge so that readers perceive that the information that they are reading in the book “reeks with reality”. In addition to vignettes that open and close each chapter, we also include other first person accounts such as:

- “My Voice Boxes”—we feature parents, individuals with a disability, brothers and sisters, teachers, administrators, related service providers, and community citizens share their personal convictions about various issues.
- “Making a Difference Boxes”—we feature individuals and teams who embrace complexity, act courageously, and make a difference in infusing supports and services throughout all environmental levels.
- “Into Practice Boxes”—we feature state-of-art strategies for translating research into everyday practice.

Throughout all of the boxes, families and professionals speak with many dialects and accents because they represent a broad spectrum of American life. They show how people of every economic and social stratum; of every color, race, and ethnic origin; in every part of this country can empower themselves and each other to enhance quality of life.

SUMMARY

In this paper, we assert that family research must be part of the new paradigm because families are among the natural environments that affect and are affected by a person who has an impairment. Knowledge is power. That much, we all know. And the world of disability is contextual. That, too, we all know. The challenge is to rebalance the power relationships between researchers and families so that the knowledge that comes from research will change the world of those affected by disability. To do that, we must recognize that the research community is itself one of those cultural and social environments that has limited—but need not continue to limit—the life opportunities of people with disabilities and their family members.

In describing the old and the new paradigms, we emphasize the relationship between professionals on the one hand and families on the other. That relationship involves certain degrees of power. We argue that, under the old paradigm, professionals had *power over* families. The psychotherapy, parent training, and parent involvement models located power within professionals and outside of families.

Under the family-centered model, however, power shifted. Theoretically, it no longer should be the case that professionals have *power over* families. Now, it should be the case that families and professionals will collaborate to address the priority needs of families as the families themselves identify those needs. Here, *power with* obtains.

Under the emerging family empowerment/family quality of life model for which we advocate here, the relationship changes yet again. No longer is *power with* sufficient. Now, *power through* occurs. Here, synergy obtains. Here, families, friends, community citizens, and professionals collaborate to “fix” environments at multiple levels (family, services, community, society, culture). We offer an analytical framework that leads to a new paradigm research approach incorporating policy analysis, explanatory research, and program evaluation and quality enhancement. Then, we offer a way to organize information for teacher education programs through our textbook that incorporates the new paradigm research—*Families, Professionals, and Exceptionality: Collaborating for Empowerment*. We are highly enthusiastic about the ultimate outcomes for families, including children and youth with disabilities, when new paradigm research leads to new paradigm teacher education which, in turn, leads to new paradigm supports, services, and, ultimately, outcomes.

DISCUSSION QUESTIONS

1. Compare and contrast the roles of families in the old and new paradigms.
2. Stand in the shoes of a parent of a teenager with Down syndrome who is graduating from high school and transitioning to adulthood. How might the application of the new paradigm make a meaningful difference in enabling you and your family to experience success with this transition?
3. Identify at least five domains of family quality of life and give an example of something that you might do as a professional to support a family in each of those domains.
4. Identify at least five core concepts of disability policy. What could you do as a practicing professional to ensure that each of those core concepts is incorporated into how you form partnerships with families?

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