Chapter 4

Enhancing Quality of Life of Families of Children and Youth With Disabilities in the United States

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A Day in the Life of the Poston Family

May 12, 2000. As I was preparing for the day ahead, I was celebrating the 2-week anniversary of our move to Lawrence from Leavenworth, Kansas. We moved here for many reasons: to be closer to work and my doctoral program, to be closer to friends, to have more and better supports for my 13-year-old son AJ, who has autism, and to leave behind some of the physical reminders of life prior to my recent divorce. I knew that we would still have challenges here. AJ would still have autism and all the joys and challenges it brings, I would still be a single mother with two boys ages 11 and 13, and I would still have the duty to make a good life for myself and my boys. But at least here I expected to have more supports.

In the 2 weeks since the move, I had interviewed case managers and selected one (in Kansas, a Medicaid recipient has a choice concerning case management agencies) and checked out the local mental health organization for counseling for my 11-year-old son, Jim. I had also called several family practice physicians, only to find out that none of the ones I called accepted my insurance coverage. No matter whom I saw, I was going to have to pay more than I paid in Leavenworth. In an effort to hire people who could assist AJ at home and in our community, I had put flyers up all over the

University of Kansas campus and telephoned student employment services, the school district, and friends.

In those same 2 weeks, AJ had an escalating number of outbursts and refused to leave the house except to go to school, an ice cream store, church, and one special friend's house where there is a Nintendo. All he wanted to do was stay home and play Nintendo. Jim was dying to make friends, and, although I reminded him that it had been only 2 weeks, it was his opinion in his all-or-nothing 11-year-old way of thinking that he would NEVER have friends again as long as he lived. The staff at both Jim's and AJ's schools had been wonderful about getting to know them, accepting them, and making accommodations that they would need to facilitate learning at school. AJ was spending more time with "typical" peers than he ever had in the past. He had even brought home a real textbook with real homework for the first time ever.

On that day when I was celebrating, AJ had another violent behavior outburst—his third in four days. It started the same way that about one-quarter of his outbursts start. He was being a little mischievous, hassling his brother and messing around with a stuffed animal. As he came outside to wait for the bus, he started throwing his book bag—a sure sign that things were escalating. I went through my normal routine of diversion and calming, but this time he did not respond.

This is the sort of behavior that I worry about. Fortunately, it doesn't happen very often, only two or three times a week. But I must be constantly on the alert, waiting for it all the time. I know that the tension that accompanies this constant vigilance takes a toll on me. It also takes its toll on Jim. During this particular incident, AJ's violent reaction to my intervention resulted in him pinning me to the ground by the bus stop, with his fist full of my hair. When I finally broke free and returned to my newly rented home, just up the street from the bus stop, I was able to call his teacher, who came right over to help calm him down. Someone also called the police. So here we were, 2 weeks in our new home, and we already had the police at our door.

That incident was a harbinger of things to come. AJ had three more of those violent outbursts later that day. The police were called three more times—once to take AJ to the local hospital, once to defuse the situation, and the last time to take him in handcuffs

to the juvenile detention facility. Many of the details of what happened that day are blurry to me. I was in a fog, physically hurting from his blows and emotionally hurting from the pain of feeling like a failure as a parent.

I also felt that I had failed to protect AJ from himself and his disability. Furthermore, I had failed to protect Jim from the emotional turmoil that accompanies each tantrum; Jim had been screaming at AJ to "Stop it, AJ! Stop hurting Mom!" Luckily, a good friend took Jim away from home early in the afternoon and kept him overnight, thereby sparing him from witnessing most of the violence—the police, the battering, the destruction.

I felt that I should have been able to handle the situation. After all, I know AJ very well and I have closely analyzed what causes his outbursts and how to defuse them. But he is getting so big and strong that I was physically almost helpless. I could only dodge his blows—not all of them, just some. A friend from work came over and was also trying to restrain AJ, but could not. I could only sit and watch and listen as my son destroyed our home. I know that money isn't the most important thing in life, but, in my household every cent counts, and I don't have extra to replace broken doors or windows, or to patch holes in the walls. None of the violence or destruction would matter at all if he seriously hurt himself, or me, or anyone else. The head of the local provider agency came over and helped us explore some options for AJ. We knew he could not stay at home alone with me. We also knew that he probably couldn't stay at home with anyone else either—the destroyed physical environment seemed to be a catalyst for more outbursts.

So my friend, the agency director, and I started looking for a safe place for AJ to stay. Our local hospital and mental health center said they did not have the capacity to keep adolescents on an in-patient basis. The head of the local agency was able to get him into the nearby state hospital for people with developmental disabilities on an emergency basis, but to admit him that night would mean a 2-and-a-half-hour drive with a violent young man at an hour when we were all exhausted—except the violent young man! The juvenile intake coordinator at the police station looked for a "bed" closer to us. She was very helpful, for she knew "the system" and coached me to use the right words, those that would get the result we needed for AJ—a short-term, emergency, in-patient facility where staff could

stabilize him, keep him safe, and give me time to recover physically and emotionally and to figure out what to do next.

To consider hospitalizing AJ, no matter how dire his and our need at the time, was a huge step for me. I felt that no one could care for AJ as I could—even though I felt that I wasn't doing such a great job at the moment. I was afraid he would not be understood, that he would be restrained indiscriminately, that he might be pumped full of medication with potentially serious side effects, and that all of this would cause him to have even more behavior outbursts. I didn't trust the mental and physical health care systems to know how to care for him.

It took the kind and gentle, but persistent, urging of my friends to help me finally understand that this was best not just for AJ, but also for Jim and me as well. It is so difficult to decide when to "sacrifice" one family member's well-being for the well-being of others. In our case, both Jim and I had been sacrificing so long for AJ. I guess now it was time for him to give a little so that we could put our lives back together.

* * *

AJ has been in the hospital a little over a week, and I am just starting to feel a little less guilty about having him there. I am using the time to rest, plan for AJ's return, do things with Jim, catch up on work, and prioritize everything that I feel I have to do to keep my life running smoothly.

This whole incident has me thinking. First of all, I want never to be in the position again where things get so bad that the only solution is out-of-home placement, even if that placement is short term. Second, I need to have supports in place for AJ and a variety of preferred activities so that I don't use the Nintendo as a babysitter. It takes so much time and effort to keep him engaged in positive activities that I can't do it alone. Either I have no time left for anything else, or I become resentful at having to spend all my time outside of work being support person, case manager, therapist, friendship facilitator, and mom.

I had already tried to find assistants for AJ. I had flyers up all over campus, sent an ad to the student employment office, and called friends of colleagues, but so far I have come up empty. There are only

a few more places I have to call. We have access to well-funded home- and community-based services, yet I cannot find qualified—or even unqualified, for that matter—people to hire as AJ's assistants. Once these assistants are in place and there are a variety of activities for AJ, then I think things will not come to a crisis again.

We are having a Group Action Planning meeting tomorrow. Our group consists of friends and professionals who meet on a regular basis to set goals and figure out "next steps" to accomplish the goals. The group did an excellent job getting me through the move to Lawrence and helping AJ's transition to the new school. But we didn't take care of the one thing I needed, which was to keep him safe at home. So that is our task now: finding a way to support AJ at home so that we all—AJ, Jim, and I—have a good quality of life. We have a lot to do at the meeting.

Denise Poston

Overview

This chapter provides an overview on policy, services, and research related to the quality of life of families in the United States who have children and youth with disabilities. It begins with an overview of the current sociopolitical trends and the current service delivery system, as of the middle of the year 2000. It then describes the Beach Center's research program on enhancing family quality of life (also as of the middle of the year 2000) and concludes by suggesting future directions for research, policy, and services. Throughout, we integrate examples of the Poston family as a way of grounding our concepts in the reality of family life, since it is our intention and hope that families everywhere will benefit from family quality of life research. Because we wrote this chapter in the beginning of the year 2000, we add a postscript to comment briefly on developments since that time.

Current Sociopolitical Trends

Families of children and youth with disabilities are affected by both general sociopolitical trends and by disability-specific trends.

General Trends

Two general trends of the 1990s have implications for family quality of life: the effects of policies that have encouraged strong economic growth, and the effects of changing views on the role of governments.

Demographics and Economics: A Mixed Picture

The United States has recently experienced greater overall economic health than at any time since the middle 1950s: the unemployment rate is

lower; interest rates are generally lower; the paper wealth of investors has increased remarkably; there is an increase in the number of first-time home buyers and people trading up to larger houses; yearly, more households become linked to the Internet; and fewer families remain on public support (in part because of the economy and in part because of the welfare-reform laws that discourage such support). One view of these trends is that they help improve families' quality of life: a rising tide has lifted all boats.

The healthy national economy has also affected the field of disability. Supported and competitive employment of individuals with disabilities is higher than at any time since World War II (Braddock, Hemp, Parish, & Rizzolo, 2000). In addition, the closure or down sizing of the state facilities for people with disabilities, the creation of more home and community residential placements, the down sizing (from 12 to 6 or fewer residents) of community residential facilities, and increases in family support are proceeding unabated, fueled largely by a community-living ideology and by an economy that makes the ideology affordable (Braddock et al., 2000).

At the same time, there are more families whose countries of origin are not English speaking, more non-Caucasian families that are regarded as poor or working poor, and more families affected by "welfare reform" than at any time in the past half century (U.S. Census Bureau, 1996). The national poverty rate is 28% for children with disabilities and 16% for children without disabilities (Fuijiura & Yamaki, 2000). Indeed, the cooccurrence of poverty, single-parent families, cultural/linguistic/ethnic diversity, and disability is undeniable and has yet to be reversed (Forum on Child and Family Statistics, 1998; Fuijiura & Yamaki, 1997, 2000; LaPlante, Carlson, Kaye, & Bradsher, 1996; Newacheck & Halfon, 1998; Sherman, 1994; U.S. Census Bureau, 1996).

Politics: Moderation and the New Federalism

In the 1990s the United States witnessed at least three very different views on the role of government (H. Turnbull & A. Turnbull, 2000). The first emphasized an increased role for the federal government. This view was exemplified by efforts of the Clinton administration to establish a policy of universal, federally sponsored, and federally subsidized health care, and the failure of these efforts appears to represent a failure of support for the view that the federal government has a place in sponsoring large national programs.

A second view on the role of government emphasized a marked decrease in political intervention. This highly conservative view was evident in the actions of the 1994 Congress (the so-called Gingrich Congress) that involved efforts to enact a new "Contract With America," under which the federal government would abandon or significantly reduce its role in education, health care, and habilitation and rehabilitation services. These efforts

also failed, signifying an apparent lack of support for reducing the role of government to such a degree.

The third view was more "moderate." This view held that the federal government has a legitimate role to play, but that it must "devolve" or transfer a great deal more discretion to operate programs that meet local needs to the states.

It seems clear at this writing that the moderate perspective has prevailed. There is increasing devolution of government rights and duties from the federal to the state-local level. This "new federalism" holds that issues that for the past 50 years have been regarded as national are in fact better handled by state and local governments. Accordingly, few new federal rights are being created. Likewise, state and local governments have increased discretion in administrating federally financed programs. One part of the key federal antidiscrimination law (Americans With Disabilities Act, 1990) was successfully challenged as unconstitutional in terms of Congress' power to enforce the equal protection provision of the 14th Amendment to the Constitution (*University of Alabama v. Garrett*, 2001). Other federal laws are being struck down as an unconstitutional exercise of federal power (*Alexander v. Sandoval*, 2001). The Supreme Court leads the way in policy making—a fact that is deeply disturbing, for its members are not subject to the corrective political process; they have life-time tenure. The federal role in disability policy is shrinking.

Disability-Specific Trends

Four trends that primarily affect individuals with disabilities and their families are the consolidation of rights, an emphasis on outcomes, the new paradigm of disability, and the linkage of core concepts and quality of life outcomes.

Consolidation of Rights

The 1970s was the "civil rights era," a time when new rights to education, habilitation, rehabilitation, and community access were first established and when the emphasis was on *access* (removing barriers) and *benefit* (assuring that an accessible society provides individualized benefits). But the 1980s and 1990s were an era of *consolidation*, a time when rights were reaffirmed or improved, thereby contributing to families' quality of life. In 2000 and 2001, the Supreme Court began to vitiate the scope of antidiscrimination laws (*Kimel v. Board of Regents*, 2000; *Alabama v. Garrett*, 2001).

During the past two decades, both Congress and state legislatures have consolidated the rights of individuals with disabilities and their families in a number of ways. In the mid-1980s, Congress amended the federal special-education statute, Individuals With Disabilities Education Act (IDEA), to provide services to infants and children and to assure smooth transitions

from school to the world of adulthood (H. Turnbull & A. Turnbull, 2000). In 1997 Congress strengthened parents' rights to share in school decision making, students' access to the general curriculum, students' protection against school discipline, and students' rights to "state-of-the-art" technology, called positive behavioral supports (H. Turnbull & A. Turnbull, 2000). In *Board v. Rowley* (1982), in *Irving Independent School District v. Tatro* (1984), and again in *Cedar Rapids Community School District v. Garret F.* (1999), the U.S. Supreme Court interpreted IDEA to sustain students' claims to an appropriate education and related services.

In 1988 Congress enacted antidiscrimination laws related to fair housing (Fair Housing Act Amendments). In 1990 it followed suit by enacting the "disability civil rights act," Americans With Disabilities Act (ADA), prohibiting discrimination in state and local governmental activities, public- and private-sector employment, transportation and telecommunications, and privately operated public accommodations.

As we said above, however, the constitutionality of these laws is now in doubt because of the Supreme Court's decisions. The era of consolidation may have been the last breath of liberalism in the United States.

Emphasis on Outcomes

The 1990s was a decade when Congress continued to emphasize process rights but added an emphasis on outcome rights. For example, when Congress first enacted the Individuals With Disabilities Education Act in 1975 (originally called the Education of the Handicapped Act), it emphasized how schools should transact their business with students with disabilities; the legal maxim "fair procedures produce fair results" governed (H. Turnbull & A. Turnbull, 2000). With the enactment of the Americans With Disabilities Act in 1990 and the reauthorization of the Individuals With Disabilities Education Act in 1997, however, Congress made clear that there are four *outcome* goals: full participation, equal opportunity, independent living, and economic self-sufficiency. Now families' quality of life is improved or affected by how well government achieves those outcome goals, not simply by how they process their services to families.

The New Paradigm of Disability

The old paradigm of disability characterizes disability as a deficit within the individual that results in functional impairments associated with daily activities (A. Turnbull, Turbiville, & Turnbull, 2000). Accordingly, it focuses on "fixing" the individual's functional impairments and "fixing" the individual's parents (usually just mother) so that the person will be able to participate in the general societal experiences and settings. Figure 4.1 depicts the old paradigm's target of intervention.
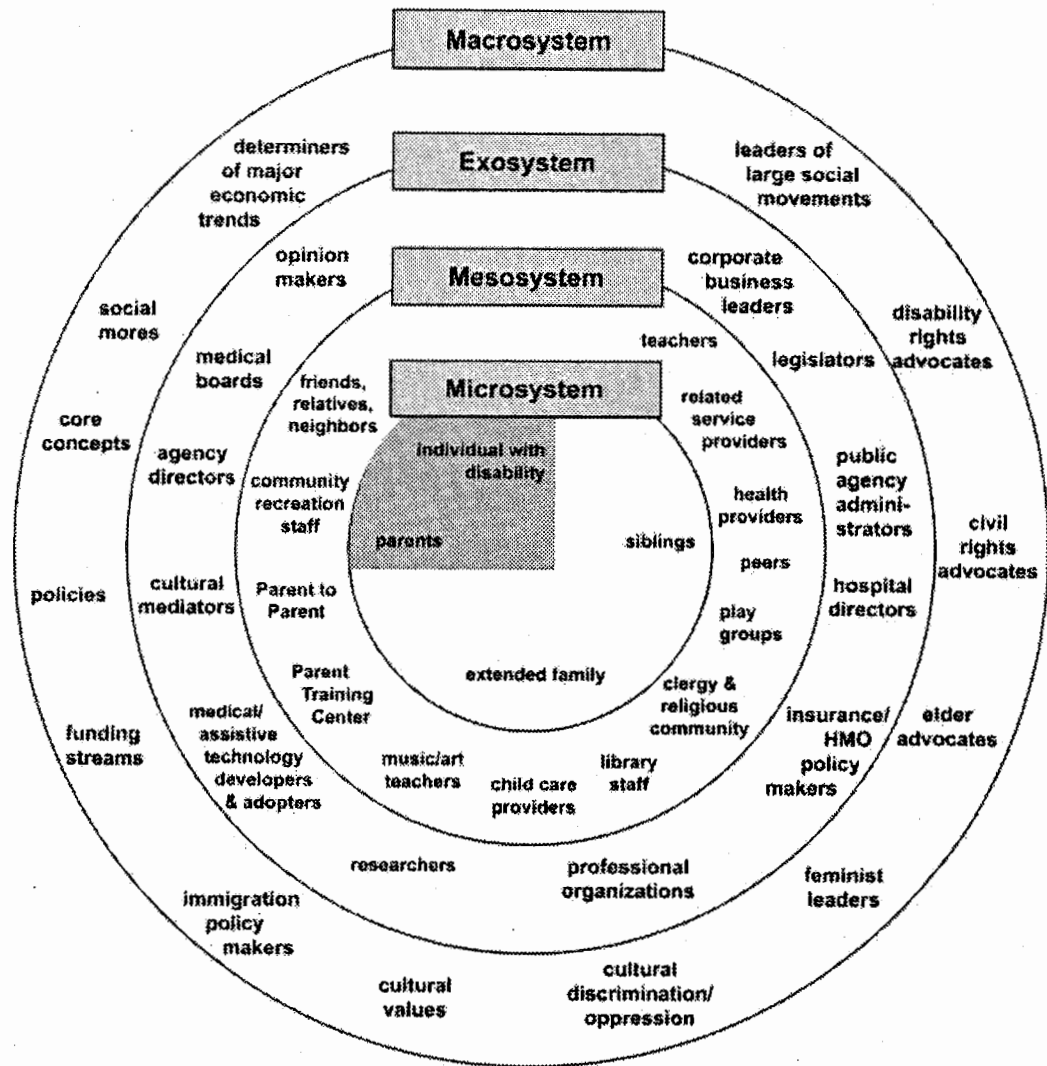
Figure 4.1 Old paradigm: emphasis on "Fixing" the individual. Shaded area represents target of "change efforts."

The Americans With Disabilities Act (1990) and a new paradigm characterize disability as contextual and societal. A person has an impairment that is not a disability if sufficient supports and accommodations are available from and within the macrosystem, the exosystem, the mesosystem, and the microsystem, as illustrated in Figure 4.2. These environments either limit or liberate individuals with disabilities and their families. This paradigm then views disability as a social reaction to impairment. It emphasizes changes from "fixing" the individual and the family to "fixing" the social, policy, and physical environments, rather than "fixing" individuals (A. Turnbull, Blue-Banning, Turbiville, & Park, 1999). "Fixing" all such environments, it is believed, assures that adequate supports, services, accommodations, and relationships are available so that people with disabilities may accomplish the four outcomes goals.
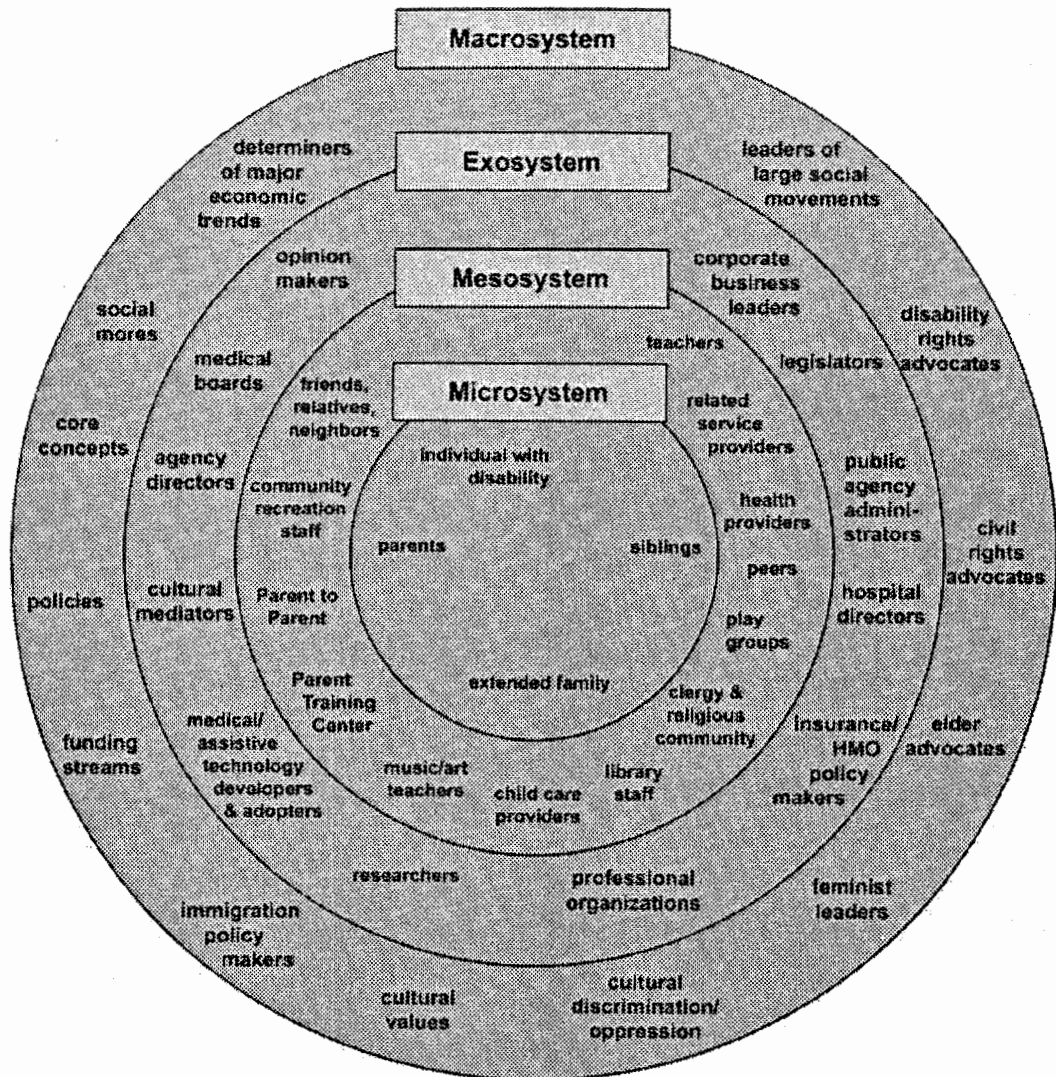
Figure 4.2 New paradigm: emphasis on "fixing" the system. Shaded area represents target of "change efforts."

Linkage of Core Concepts and Quality of Life Outcomes

The new paradigm recognizes that policy is a critical aspect of the environment in which people live. For this reason, it seeks to ground policy and practice explicitly in disability core concepts, and to link these core concepts to individual and family quality of life outcomes (H. Turnbull, Stowe, & Beegle, 2001). For example, the Individuals With Disabilities Education Act changed the policy and service-delivery environments (schools) by articulating the core concepts of disability policy and by authorizing services grounded in these concepts and targeted at outcomes. Furthermore, as illustrated by IDEA, the new paradigm also changes the family environment by strengthening families' rights with respect to their children's education. By changing the policy and service environments, advancing core concepts of

policy, and assuring that policy and services target designated outcomes, the new paradigm addresses individual and family quality of life. We will discuss core concepts and family quality of life outcomes in the section that focuses on our current research agenda.

Current Service-Delivery Trends

The sociopolitical trends described above heavily influence current trends in service delivery.

General Trends

Partnerships

Traditionally, discrete laws and funding streams have sought to address narrowly targeted problems. Thus there are separate laws and appropriations for general education, special education, mental health, public health, social services, and others. These create a system of "verticality"—narrowly targeted problems and narrowly constructed policies, services, and funding streams. Table 4.1 illustrates this verticality in terms of the Poston family. The problem is that the Poston family does not fit into discrete vertical niches. This family, and indeed all families, typically have "horizontal" needs that are not sufficiently satisfied by verticality. Policies and services have dealt with only segments of families and children's lives; a wholistic approach has been elusive.

The general trend at the present time, however, is toward horizontality: cooperation, coordination, collaboration, integration, and transformation through such techniques as school-linked services, community-linked services, full-service schools, wrap-around services, and "bundling" (consolidation) of funding from different streams (Adelman & Taylor, 1997; Amato, 1996; Briar-Lawson, Lawson, Collier, & Joseph, 1997; Calfee, Wittwer, & Meredith, 1998; Coltoff, 1998; Comer, Haynes, Joyner, & Ben-Avie, 1996; Doktor & Poertner, 1996; Dryfoos, 1996, 1997, 1998; Dupper & Poertner, 1997; Franklin & Streeter, 1995; Lawson & Briar-Lawson, 1997; MacKenzie & Rogers, 1997; Raham, 1998; Sailor, in press; Skrtic & Sailor, 1996; U.S. Department of Education, 1999). We use the term *partnerships* to describe the gestalt, the general tenor, of horizontal organization.

The trend toward partnerships cuts across such diverse human-service fields as education, mental health, early childhood community development services, welfare reform demonstrations, and other poverty-related programs. Although some communities have achieved a degree of partnership, a truly service-integrated community, supporting families comprehensively, remains an unrealized ideal (Kagan, Goffin, Golub, & Pritchard, 1995; Schorr, 1997), especially for families of children with disabilities.

Table 4.1
Poston Family Needs in Three Service System Strands

Education	Human and Social Services	Health Care
• Updated and appropriate IEP for AJ incorporating behavior supports and goals • 12-month school year for AJ • Updated and appropriate IEP for Jim that focuses on supports that assist him without calling attention (from peers) to his need for support • Transportation to school for both boys that does not cause conflicts in daily schedule or childcare routines • Denise's continuing progress in her doctoral program	• New billing services for the HCBS waiver • Keeping track of upcoming changes in the HCBS system that affect the type and amount of services to which AJ is entitled • Coordination that allows AJ's participation with supports in a variety of community activities such as parks and recreation, equestrian therapy, scouting and the local youth sports "club" • Jim's participation in a variety of community activities such as swimming lessons, scouts, Big Brothers–Big Sisters, and music lessons • Supports for AJ so that all family members can actively participate in their church • Follow-up with juvenile justice regarding funding that may be available as a result of AJ's detention • Sexuality education for AJ • Regular respite care for Denise to have time with Jim, alone, and with friends • Finding and training AJ's personal assistants to provide supports at home and in the community	• Psychopharmacologist for AJ to prescribe appropriate medications that do not have side effects (drowsiness) that impact his ability to participate at school and in community activities • Counseling for Jim regarding his feelings about AJ and about his own diagnosis of ODD • Counseling for Denise • Keeping up to date on status of private medical insurance and Medicaid claims • Minimize drive time to obtain low-cost (free) medications (currently requires 45- minute one-way drive) • Family practice doctor to see the Poston family for first-line illness and injuries • Gynecologist for Denise • Dentist for the Poston family, one who is good with patients with disabilities or tactile sensitivities

Note. IEP = individualized education plan. ODD = oppositional defiant disorder.

Emphasis on Outcomes

An emphasis on outcomes is a sociopolitical trend and also a service delivery trend that has occurred simultaneously with the trend to service integration (Schorr, 1997).

This trend toward outcomes affects the disability service delivery system. For example, IDEA requires statewide or districtwide assessments of student outcomes. These assessments hold schools accountable for improving the outcomes for all students (Erickson, 1998; McLaughlin, 1998; H. Turnbull et al., 2001). Although students with disabilities have typically been excluded from state and national assessments, they are now included, and schools are held accountable for their outcomes (Vanderwood, McGrew, & Ysseldyke, 1998).

Disability-Specific Trends

The most significant trend for families has been away from the old paradigm of emphasizing parent involvement as a way to "fix" individuals with a disability to the new paradigm of family-centered services as a vehicle for "fixing" multiple environments.

Parent Involvement

When IDEA was first enacted in 1975, it authorized shared educational decision making by entitling parents to be members of their child's individualized education program (IEP) team. Although the IEP process was intended to provide a context for equal decision making among parents and professionals, a professional-dominated approach is prevalent, and there is scant evidence that the IEP process has empowering outcomes for students, parents, or educators (Smith, 1990; National Council on Disability, 1995; H. Turnbull et al., 2001). Moreover, the parents involved in educational decision making have been primarily mothers who have had limited influences on the decisions that are made in IEP conferences, mediation, and due process hearings (Able-Boone, 1993; Campbell, Strickland, & La Forme, 1992; H. Turnbull et al., 2001). This professionally dominated approach is particularly problematic for families from culturally and linguistically diverse backgrounds (Harry, Kalyanpur, & Day, 1999; Kalyanpur & Harry, 1999). It appears to exacerbate differences between the bureaucratic special-education culture and families from culturally and linguistically diverse backgrounds that rely more on relationships than legal procedures.

From Parent Involvement to Family-Centered Services

Since the mid-1980s the trend has been to move from parent involvement to family-centered services. We quote from a 1987 passage (A. Turnbull & Summers):

The term parent involvement sums up the current (1987) perspective. It means we want parents involved with us. It means the service

delivery system we helped create is at the center of the universe, and families are revolving around it. It brings to mind an analogy about the old Ptolemaic view of the universe with the earth at the center ... Copernicus came along and made a startling reversal—he put the sun in the center of the universe rather than the Earth. His declaration caused profound shock. The earth was not the epitome of creation; it was a planet like all other planets. The successful challenge to the entire system of ancient authority required a complete change in philosophical conception of the universe. This is rightly termed the "Copernican Revolution." Let's pause to consider what would happen if we had a Copernican Revolution in the field of disability. Visualize the concept: The family is the center of the universe and the service delivery system is one of the many planets revolving around it. Now visualize the service delivery system at the center and the family in orbit around it. Do you see the difference? Do you recognize the revolutionary change in perspective? We would move from an emphasis on parent involvement (i.e., parents participating in the program) to family support (i.e., programs providing a range of support services to families). This is not a semantic exercise—such a revolution leads us to a new set of assumptions and a new vista of options for service. (pp. 295–296)

The family-centered model is characterized by family choice, a family-strengths perspective, and the family as the unit of support (Allen & Petr, 1996). First, the family-centered model encourages 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, & Demmit, 1993; A. Turnbull et al., 2000). Second, the family-centered model abandoned a pathology orientation and adopted a strengths orientation (Bailey & McWilliam, 1993; Dunst, Trivette, & Deal, 1988; Saleeby, 1996). Third, the entire family is the unit of support, not just the child with a disability and the child's mother (A. Turnbull & H. Turnbull, 2001).

The trend toward family-centered services reflects the new paradigm, emphasizing the family as an environment within and to which supports and services need to be provided to mitigate the effects of disability.

Currently the family-centered model prevails in early intervention and early childhood services for young children with disabilities (McWilliam, Lang, Vandiviere, Angell, Collins, & Underdown, 1995; Murphy, Lee, Turnbull, & Turbiville, 1995; A. Turnbull et al., 2000; Wehman, 1999). Research indicates, however, that the family-centered philosophy is stronger than its actual implementation (Katz & Scarpati, 1995; McBride et al., 1993; Menke, 1991). Moreover, 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 an equalization of the power relationship between families and professionals (A. Turnbull & H. Turnbull, 2001).

Family Quality of Life Research Program

In this section we show how our research on family quality of life is consistent with the new paradigm trends we have just described. To make that point, we first describe how we carry out our research for, with, and on behalf of families: participatory action research. Then we describe the analytical framework for our research. Finally we describe the research agenda that emanates from our analytical framework.
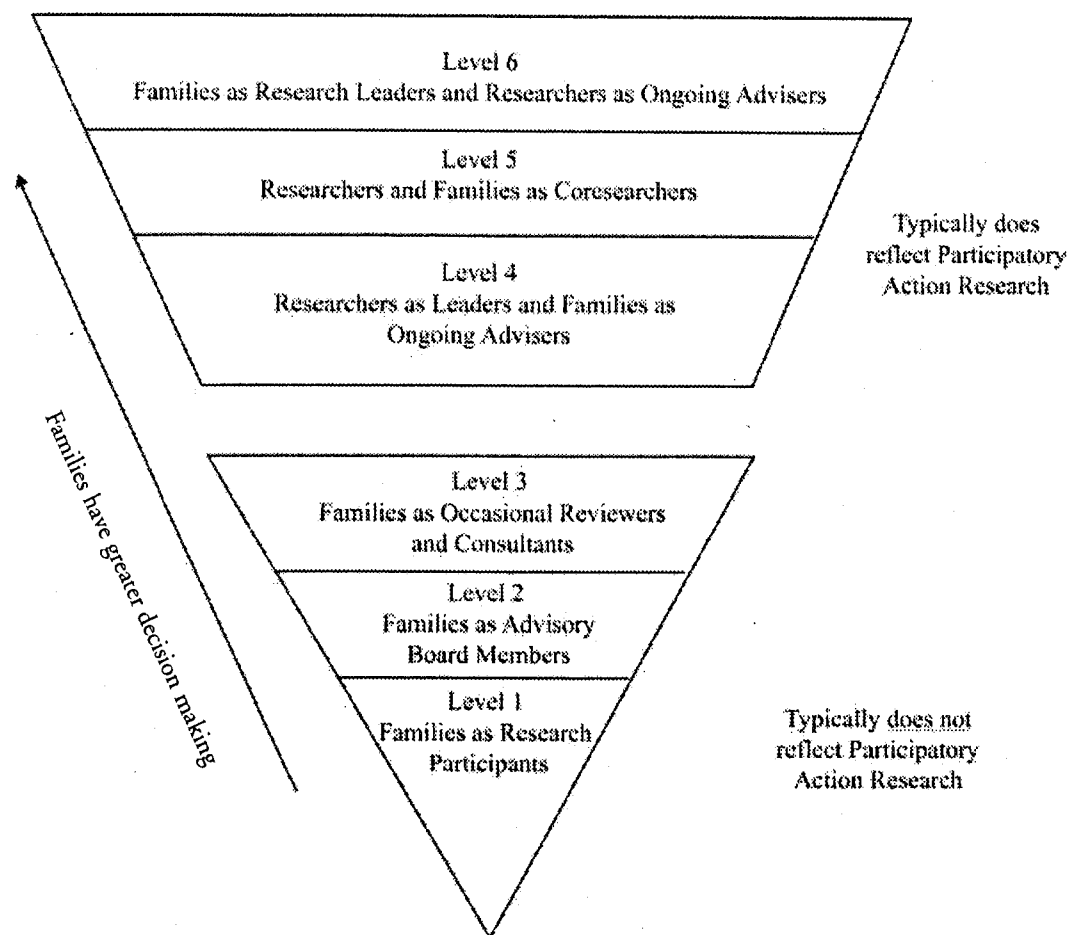
Participatory Action Research

The new paradigm acknowledges that research is itself an environment that affects individuals with disabilities and their families. A means for improving the research environment is participatory action research (PAR). Under PAR, the ultimate beneficiaries of research (individuals and families) are involved in all stages of the research (Santelli, Singer, DiVenere, Ginsberg, & Powers, 1998; A. Turnbull, Friesen, & Ramirez, 1998; H. Turnbull & A. Turnbull, 1989). Figure 4.3 illustrates six levels at which families and researchers can interact; three levels place researchers in the dominant role (old paradigm) and three represent researcher-parent partnerships (new paradigm). At the Beach Center, we work at Levels 4 through 6. Our work has particularly been influenced by the perspectives of families from culturally and linguistically diverse backgrounds that have not typically been part of the research process (Markey, Santelli, & Turnbull, 1998).

Overview of Analytical Framework

Participatory action research is one way we have improved our research environment to advance families' quality of life. Another way is assuring that all research has a common basis. We call that basis our analytical framework. Its role is to organize our research into a coherent and comprehensive whole. In the old-paradigm research environment in social services, investigators worked in relative isolation from each other, even when they were working in the same research center. The result was that the benefits to the ultimate beneficiaries of the research (in our case, families of individuals with disabilities) usually were not commensurate with the researchers' efforts or the dollars invested. To achieve outcomes that more positively affect families' quality of life, we changed our own research environment by adopting an analytical framework to assure that all of our research projects connect to each other. The new paradigm demanded nothing less. Our analytical framework has four major components (see Figure 4.4): core concepts and overarching principles of disability policy, public policy, services, and family quality of life outcomes.

Figure 4.3 Continuum of family participation in research. From "Participatory action research," by A. P. Turnbull, B. J. Friesen, and C. Ramirez, 1988. *Journal of the Association for Persons with Severe Handicaps, 23,* pp. 178–188. Copyright 1998 by The Association for Persons With Severe Handicaps. Reprinted with permission.

The first component consists of research to identify the core concepts of disability policy. A concept is an abstract or generic idea generalized from particular instances; a concept is core if it is a central and often foundational part of disability policy, and if it reflects fundamental values—values that advance the quality of life for citizens with disabilities and their families and that are widely recognized as necessary for life, liberty, and the pursuit of happiness (Brakel, Parry, & Weiner, 1985; Levy & Rubenstein, 1996; Minow, 1990; Silverstein, 2000; H. Turnbull & A. Turnbull, 2000; H. Turnbull, Stowe, & Beegle, 2001).

The core concepts merge into principles that affect all families. A principle by definition is a comprehensive and fundamental law or doctrine; accordingly, core concepts of disability policy form into a taxonomy of principles affecting all families. Thus whatever principles govern and advance the
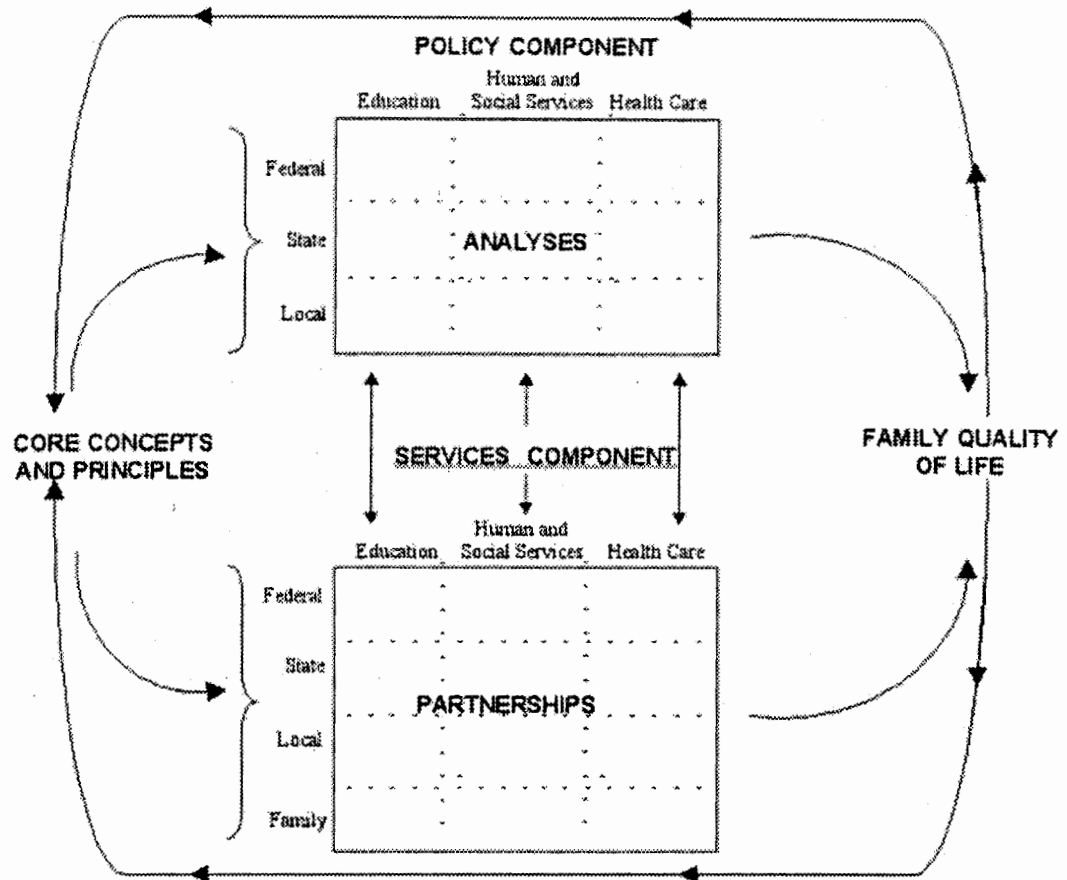
Figure 4.4 New paradigm analytical framework for enhancing family quality of life.

quality of life of all families should also do the same for families affected by disability. (Figure 4.2 places core concepts and generic principles at the macrosystem level, because they pervade not only that system but the other three systems as well.)

The second component of our analytical framework consists of research on public policy. Our assumptions here—assumptions that are central to our research agenda—are that core concepts and generic principles affect public policy; that core concepts and generic principles should be infused into policy at federal, state, and local levels (vertical implementation); and that they also should be infused across three service delivery strands: education, human and social services, and health care (horizontal implementation).

The third component of the analytical framework consists of research on service delivery systems. Because of the apparent benefits of partnerships among individuals with disabilities, families, and services providers (Adelman & Taylor, 1997; Burns & Goldman, 1999; Calfee et al., 1998; Dryfoos, 1997, 1998; Sailor, in press; Stroul, 1996), we are especially interested in the factors that facilitate or impede partnerships. We are also interested in how

policy reforms, consistent with the core concepts and generic principles, can produce better outcomes through better service-delivery structures. In particular, we believe that partnerships that address interpersonal and structural components at the family-service provider, intra-agency, and interagency levels can empower families and professionals alike.

The fourth component of our analytical framework consists of research into family quality of life. We define a quality family life as occurring when the family's needs are met, family members enjoy their life together as a family, and family members have the opportunity to pursue and achieve outcomes that are important to their happiness and fulfillment.

There appears to be general agreement that a positive family quality of life should be an outcome of policies and services (Bailey et al., 1998; Accreditation Council, 1995; A. Turnbull et al., 1999; H. Turnbull & Brunk, 1997). 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; Brown, 1997; Cummins, 1997; Felce & Perry, 1997; Gardner & Nudler, 1999; Renwick, Brown, & Nagler, 1996; Schalock, 1996, 1997, 2000). Researchers are just beginning to conceptualize and develop a taxonomy and a corresponding measurement system for family quality of life domains and indicators and thus for policy and program outcomes.

Our theory of change related to family quality of life outcome is as follows:

1. Core concepts of disability policy and overarching generic principles should shape policy (statutes, regulations, and court cases) at the federal, state, and local levels, and across the three strands of education, social services, and health care.
2. Policy shapes service delivery structures and processes at the federal, state, and local governmental level and 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 infused with the core concepts and principles, provide for horizontal implementation, and are delivered through partnerships.
4. Family quality of life domains or indicators should influence and be integral to core concepts and principles, so that, in turn, the core concepts' and generic principles' impact on policies and services will advance family quality of life.
5. Accordingly, there should be an unbroken loop in the relationship among core concepts and generic principles, policies, services, and family quality of life outcomes.

Our new research paradigm, then, relates to the outcomes of the new paradigm. Fundamentally we seek to "fix" multiple environments (see Figure 4.2) through new-paradigm research, rather than to "fix" the child or family, as was characteristic of old-paradigm research. We emphasize how research can result in a transformed ecology within which families, including children and youth with disabilities, can flourish as they interact with professionals within a responsive policy and service-delivery context (Garlow, Turnbull, & Schnase, 1991; Jones, Garlow, Turnbull, & Barber, 1996; A. Turnbull et al., 1999; H. Turnbull, Garlow, & Barber, 1991).

The Analytical Framework as a Basis for Research Activities

Our analytical framework (Figure 4.4) is the basis for our research on understanding and then enhancing family quality of life. Inherent in our research are efforts to develop measurement tools and to use them to carry out a research agenda that consists of policy analysis, explanatory research, and program evaluation or quality enhancement.

Development of Measurement Tools

Overview. Perhaps the main reason that family quality of life research is in its infancy is that very little work has occurred in conceptualizing it and advancing a corresponding measurement system. Table 4.2 shows three studies we are carrying out, in which we have developed scales, indices, and matrices that we will use in our research.

- *Scales* have a validated factorial structure with domains and respective indicators. They will be used for explanatory research involving structural equation modeling.
- *Indices* are developed from the factorial structure of scales. They are shorter than scales and will be used for policy analyses or enhancement and program evaluation or enhancement.
- *Matrices* have been developed to assess the extent to which the core concepts of disability policy and domains of family quality of life are incorporated into federal and state statutes.

Table 4.2 gives a synopsis of our three research studies on developing measurement tools. It identifies the purpose, key research questions, research design, and current findings that have been or are being developed. To put our work into context, we briefly highlight the findings from each of these studies and then relate them to the Poston family.

To identify and define the core concepts of disability policy, we (a) analyzed the Constitution of the United States, Bill of Rights, and 58 cases from the U.S. Supreme Court or other precedent-setting decisions of other courts interpreting these documents; (b) analyzed nearly 45 Acts of Congress or pending bills; (c) carried out a literature review; and (d) conducted focus groups and individual interviews with policy leaders, senior-level program

Table 4.2
Overview of Studies to Develop Measurement Tools

Study Focus	Purposes	Key Research Question	Research Design	Current Findings
Core Concepts	• To identify and define the core concepts of disability policy affecting families that have children with disabilities • To develop measurement tools related to the core concepts	• What are the core concepts—definitions, appropriate synonyms, and bases in key statutes, judicial cases, and practice?	• Focus groups and individual interviews consistent with rigorous qualitative procedures • Conduct test-retest reliability on the family and service provider indices • Conduct inter-rater reliability on the matrix for policy analysis	• Data confirm 18 core concepts, reveal 250+ factors influencing policy, and demonstrate inter- relationships of concepts, factors, and family quality of life outcomes
Partnerships	• To confirm or modify a conceptual model of partnerships between and among families and professionals • To identify domains and indicators associated with the components of partnerships • To configure the domains and indicators into scales and indices	• What are the domains and indicators of exemplary partnerships at the family-service provider, intra-agency, and interagency levels?	• Identified preliminary domains through literature review and PAR committee • Conducted 34 focus groups with parents, individuals with disabilities, service providers, and administrators (N = 169) • Conducted individual in-depth interviews with siblings and 20 parents with limited English proficiency • Constructed, pilot tested, and revised preliminary scale of family-service provider partnerships • In process of conducting large-scale field test • Will use confirmatory factor analysis to analyze responses	• The focus group data suggest six domains (with 10 indicators per domain) at the family-service level: communication, trust, respect, commitment, equality, and skills • The focus group data suggests a shift in our original conceptualization of interpersonal partnerships; Interpersonal domains appear to be homogeneous at family-service provider, intra-agency, and interagency levels

Family Quality of Life	• To identify domains and indicators of family quality of life
	• To configure the domains and indicators into a scale, indices, and matrix
		• What are the domains and indicators of family quality of life for children with disabilities?	• Same as partnerships except for the following:
			  – A minimum of 750 families will be involved in the field test
			  – All family members will be asked to complete a scale rather than only the primary care provider
				• Focus group data suggest a conceptualization of family quality of life with 10 domains, divided into two groups: those that primarily focus on the family as a unit and those that focus on individual members' impact on the family
				• The domains for the family as a unit are family interaction, daily life, parenting, and financial well-being
				• The domains for individual family members are emotional well-being, health, physical environment, productivity, social well-being, and advocacy

Note: PAR – participatory action research.

administrators, and family advocacy organization leaders at the federal and state-regional levels (H. Turnbull et al., 2001). Table 4.3 identifies and briefly defines the 18 core concepts; Table 4.4 indicates how six core concepts relate to family quality of life (as exemplified by the Poston family) and how the core concepts can conflict with each other when applied.

Table 4.3
Core Concepts of Disability Policy

Disability Policy Core Concepts Principles	Definition and Constitutional
Antidiscrimination	Statutes, generally known as "civil rights acts," make it illegal to discriminate against a person with a disability solely by reason of the person's disability.
Autonomy	A person with a disability or the person's family has a right to consent, refuse to consent, withdraw consent, or otherwise control or have choice over what happens to him or her. Sometimes the concept of autonomy is expressed as "independence," "self-determination," or "full participation."
Empowerment/ Participatory Decision Making	These are the means by which a person or family or a duly appointed surrogate secures what he or she wants from a service provider system; the means is through participation with the system in consenting (see "autonomy") or otherwise participating in the decision-making processes by which the services that will be received are planned, developed, implemented, and evaluated.
Privacy & Confidentiality	Privacy refers to protection against unwarranted governmental interference in decision making that affects private interests. Confidentiality refers to information concerning one' self or family; it includes the person's or family's access to the information, rights of correction and expungement, and control over access to it by others.
Liberty	A person has the right to be free from unwarranted physical or other confinement by a government. Related is a claim to be treated with respect and dignity.
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.

(table continues)

(table 4.3 continued)

Disability Policy Core Concepts Principles	Definition and Constitutional
Individualized & Appropriate Services	These services are specially tailored to meet the needs and preferences of individuals with disabilities and their families.
Capacity-Based Services	The evaluation of the unique strengths and needs of a person with a disability or the person's family is the basis for capacity-based services. It includes a person- or family-directed evaluation of their resources, priorities, and concerns and their identification of the services necessary to enhance their various capacities. The term reflects the "strengths" perspective and rejects the "pathology" perspective.
Classification	Classification includes the 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 (antidiscrimination or other rights or entitlements). Sometimes eligibility is based on the severity of a person's disability or the family's extent of need.
Productivity & Contribution	Productivity refers to engagement in income-producing work and contribution refers to unpaid work that benefits a household or community. A synonym for productivity is economic self-sufficiency.
Integration	A person with a disability has the right not to be segregated, solely on the basis of disability, from people who do not have disabilities and not to be barred from participation in services that serve people who do not have disabilities. The prohibition against segregation includes a mandate for integration into generic services (as appropriate) and into the most typical environments (as appropriate).
Family Integrity & Unity	Policy presumes in favor of preserving and strengthening of the family as the core unit of society. That policy is reflected in services that maintain the family intact, assure responses to all family members, and respond to the family based on its cultural, ethnic, linguistic, or other socioeconomic traits and choices. Related are the concepts of family centeredness and cultural responsiveness.

(table continues)

(table 4.3 continued)

Disability Policy Core Concepts Principles	Definition and Constitutional
Family-Centeredness to Services to Whole Family	These services respond to the needs of the entire family of a person with a disability. They (a) support families to raise their children with disabilities in the family home, (b) strengthen the role of the family as the primary caregiver, (c) maintain the family's intactness and unity, and (d) reunite families with their children who have been placed out of the family home.
Service Coordination & Collaboration	Activities assist individuals with disabilities or their families to access and then to benefit from services from more than one provider system (interagency) 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 therefore have the greatest likelihood of ensuring maximum participation of and benefit to the person or family.
Accountability	Accountability includes various methods of achieving the specified outcomes of services, especially procedural safeguards (legal accountability via procedural due process) and program-improvement measures.
Prevention	Prevention services seek primary, secondary, and tertiary prevention of disability.
Capacity	A service delivery system should have the capacity to implement any one or more core concepts, as appropriate for that system.

We have identified the following 18 core concepts of disability policy: (a) antidiscrimination, (b) autonomy, (c) empowerment, (d) privacy and confidentiality, (e) liberty (physical), (f) protection from harm, (g) individualized and appropriate services, (h) capacity-based services, (i) classification, (j) productivity, (k) integration, (l) family integrity, (m) family centeredness, (n) coordination and collaboration, (o) cultural responsiveness, (p) accountability, (q) prevention, and (r) professional capacity. Together these core concepts form the necessary components of policy that we assume, theoretically, to advance the quality of life of individuals with disabilities and their families.

Table 4.4
Illustrative Core Concepts as They
Relate to the Poston's Family Quality of Life

Service Coordination and Collaboration

Without service coordination, AJ might not benefit from the many services and supports that are available (productivity domain), and Denise would be very stressed trying to do it herself or feel guilty that she could not do it herself (emotional well-being domain). The specific tasks involved are to (a) find, hire, and train assistants for AJ, (b) put together a schedule of activities and goals at home and in the community that are coordinated with AJ's educational activities and goals, and (c) manage, supervise, and coordinate and be accountable to AJ, Denise, and the other support team members.

Protection From Harm

Family-Centeredness

Integration

Family Integrity

During AJ's aggressive outbursts, he has the potential to harm himself and other family members, especially Denise (physical environment domain). Here there is a tension between the core concepts. By temporarily admitting him to the hospital, the Poston family chose to partially limit AJ's integration into the family (family interaction domain) and community as well as suspend family integrity so that (a) all family members can be safe, (b) the Poston family can be strengthened through supports and services, and (c) AJ can get a thorough psychopharmological evaluation.

Empowerment

The Poston family has chosen to convene a GAP (Group Action Planning team, which is a form of person-centered planning) to bring together friends and professionals from different service systems on an informal basis (advocacy domain and social well-being domain). The GAP serves to (a) bring information and options to the group, (b) provide input and support for Denise as she participates in the decision-making processes of the service systems, and (c) assist with service coordination.

These 18 core concepts of disability policy reflect nine principles. The first three principles—life, liberty, and equality—mirror the doctrines of our federal (written) Constitution, are the fundamental law of the land, and reflect our cultural, political, philosophical, and legal traditions. These are the *Constitutional principles*. Three other principles—dignity, family as foundation, and community—reflect widely held societal ethics, values, beliefs, and ideals. These are the *ethical principles*. The last three principles—capacity,

individualization, and accountability—incorporate the qualities (capacity), foci (the individual beneficiaries), and procedures (legal and other accountability safeguards) that must be included in any policy to support its successful implementation. These are the *administrative principles*.

In addition, we have identified from our respondents' comments approximately 200 factors that facilitate, impede, and in other ways affect the development and meaning of core concepts and the translation of the core concepts into practice (e.g., administrative changes, shortfall in budget). These influencing factors affect policy development implementation, service delivery, and systems change across all sectors of the human service system.

To help policy makers, program administrators, and policy advocates apply our research on core concepts, we are developing three tools to measure core concepts: a matrix and two indices. *The Disability Policy Core Concepts Matrix for Policy Analysis* performs two levels of analysis: (a) the extent to which it is *appropriate* for a federal or state statute to reflect specific disability policy core concepts, and (b) the extent to which the statute reflects *coherence* with disability policy core concepts.

Because statutes have different purposes, it is not *appropriate* for every disability policy core concept to be incorporated into every statute. For example, it is arguably more *appropriate* for IDEA to reflect the concept of productivity than it is for the Developmental Disabilities Assistance and Bill of Rights Act (1995) 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 Developmental Disabilities Act creates statewide, 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 are *coherent* with respect to core concepts. Coherence addresses the consistency with which statutes incorporate the disability core concepts throughout all of their parts. For example, the administrative provisions of the law can align closely or weakly with the law's basic provisions, thus strengthening or weakening its implementation of core concepts. Thus coherence recognizes both the incorporation of the core concepts and internal consistency of adherence to the core concepts.

The two indices—*Disability Policy Core Concepts Index for Families* and *Disability Policy Core Concepts Index for Service Providers*—enable families and services providers, respectively, to assess the extent to which they believe it is important to incorporate the *appropriate* core concepts into service delivery and the extent to which they are satisfied that the *appropriate* core concepts are being *coherently* incorporated.

Measurement Tools for Partnerships. We began the process of developing partnership measurement tools by thoroughly reviewing partnership-related

literature. Our review led us to conceptualize partnerships in the way that is shown at the top of Figure 4.5. This original conceptualization depicts partnerships at three commonly accepted levels—family members or service provider, intra-agency, and interagency. It also categorizes partnerships into interpersonal or structural components. Finally it suggests that cooperation, coordination, collaboration, and integration exist on a continuum from minimal to maximal partnerships, and it reflects our assumptions that service integration represents the most intensive level of partnership at the interagency level and that transdisciplinary teams are the most intensive partnerships at the intra-agency level.

Through our focus groups and individual interviews with family members and professionals, we identified six partnership domains and indicators associated with each domain. Table 4.5 reflects our analysis of the data from the focus groups and interviews. It identifies each domain and the associated indicators; it also exemplifies (via the Poston family) how these domains and indicators can impede or facilitate family quality of life. Figure 4.6 shows the process we followed to develop the partnership scale.

Our data suggested that our original partnership conceptualization (Figure 4.5) was inaccurate in terms of interpersonal partnerships at each of the three levels. Originally we hypothesized that the interpersonal partnerships would be different at each level and would therefore require different measurement tools. In our focus groups and interviews, however, family members and professional participants alike spoke about communication, trust, respect, commitment, equality, and skills or competence in very similar ways, whether they were talking about coworkers on the team, colleagues on an interagency planning group, or parent-professional relationships. We concluded that the characteristics of interpersonal partnerships may be universal across all levels of partnership—hence, our revision of the partnership model as shown in the bottom of Figure 4.5.

We are designing two parallel scales. The *Interpersonal Partnership Scale: Family-Professional* will be completed by families and will focus on family-to-professional partnerships. The *Interpersonal Partnership Scale: Professional-Professional* will focus on professional-to-professional partnerships and will be applicable to both intra-agency and interagency relationships. We also are developing a series of indices that will be helpful to families, agencies, and professionals to assess their satisfaction with the partnerships in their organizations and community and to identify areas for program enhancement.

We are field testing each scale in eight states, including a range of urban, suburban, and rural settings. We are asking each of 300 families to identify the primary care provider (or a coprimary care provider if this role is shared) who has the major interaction with professionals in services that the child with the disability receives. The *Interpersonal Partnership Scale: Family-Professional* asks respondents to rate the importance of items to

them. To determine the factional validity of this scale, we are conducting a confirmatory factor analysis. The primary purpose of this confirmatory factor analysis is to help us determine if the indicators that we conceptualized as "fitting" in each domain are actually appropriately related to that concept. In addition, we hope to be able to make comparisons about the degree of importance parents place on these domains of interpersonal partnership at different child ages and on different types of services (health, education, or social services). We also hope to be able to determine whether families from different socioeconomic backgrounds, ethnic groups, and geographical locations differ in the relative emphasis they give to these domains of partnership.

Table 4.5
Domains and Indicators of Interpersonal Partnerships

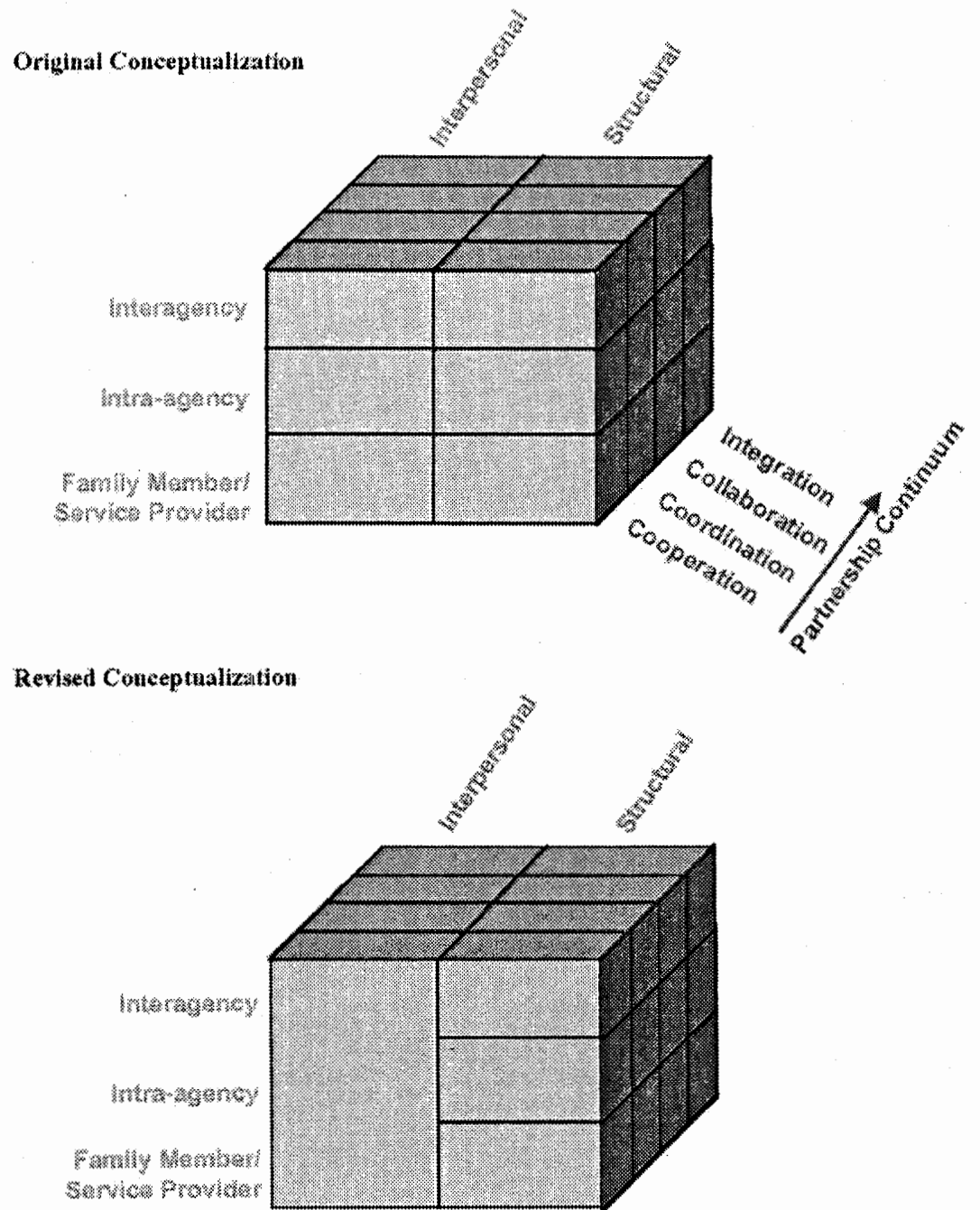| Domains and Indicators	Examples of Positive and Negative Partnerships
Communication • Resource sharing • Honesty • Clarity • Listen • Information coordination • Positive communication • Openness • Frequency	"AJ's new teacher and I have a longstanding relationship that started before AJ started at school there. I know he will really tell me like it is...it may take a while for him to find the best way to say something, but he is always honest with me about what he thinks is best for AJ." "There is nothing worse than people not returning phone calls. When I was trying to choose a case manager for AJ, people I called from several agencies never returned my calls. I don't want to have to fight for such a simple thing as returning calls."
Trust • Reliability • Safety • Discretion	"Before we moved, AJ had a behavior consultant whom both he and I could count on. She would come over to the house if AJ were having an episode. She always followed through on what she said she was going to do—training staff, developing instructional materials, or just calling to check on us." "When AJ was having some trouble in the self-contained class, the special-education director recommended a "distraction-free work area." This sounded like a good idea to me, . . . but when I finally went to see it, what I saw was the time-out booth they had built for him several years ago—a padded 6-foot-square box that he spent most of his day in. After that, I knew I had to question everything this person said to me."

(table continues)

(table 4.5 continued)

Domains and Indicators	Examples of Positive and Negative Partnerships
Respect • Child valuing • Courtesy • Non-intrusion • Nonjudgmental • Nondiscrimination	When AJ was having a series of violent tantrums and we had to call the police, I was so afraid that, once we got involved in the law enforcement system, both AJ and I would be lost in the bureaucracy of a system that deals with people who are not generally very nice people. I expected to feel like we didn't belong there. But they made me feel very at ease, treated me with respect—I had expected to be treated like a criminal, but I was treated as a mom who was going through a rough time with her son. Both the police officer and the juvenile intake coordinator were very nice, seemed caring, and understood that it was a difficult time for both of us. I'm calling officer Matt's supervisor and to let him know how good officer Matt was with AJ. This whole experience has really eased my sense of dread concerning the police." "At AJ's school in our old community, it was clear to both AJ and me that his teacher did not like him. She saw him only as a bundle of behavior problems. All her notes to me were negative, what bad behavior he had, what work he didn't complete; she never saw him as having potential. She didn't share at all in the vision I had for him. That, more than anything else, contributed to my feeling that I could never make positive things happen for him as long as she was there."
Commitment • Commit • Access • More than job • More than a case • Encourage • Consistent • Flexible • Sensitive	"When we were getting ready to move to the new community, we were talking about how best to prepare AJ for the transition. We all agreed that he should come visit the new school before he started, get to know some of the teachers and students, and get to know his way around. I thought that task would fall to me. But the behavior consultant, who really wanted AJ to succeed, volunteered to arrange her schedule to be with him for a whole day. She even drove him over there in her car. Since the move, we have kept in touch. She is one of AJ's 'cheerleaders'." "When I was interviewing case managers after the move, one let me know that she would not be available for any evening meetings at all. It made me feel like she really didn't care about the families she was working with."

(table continues)

(table 4.5 continued)

Domains and Indicators	Examples of Positive and Negative Partnerships
Equality • Clout • Validation • Reciprocity • Harmony • Empowerment • Options • Advocate • Place to the table • Equal	"I've always felt like an equal member of AJ's IEP team, but when Jim was evaluated for special education, the staff, especially the school psychologist, counselor, and resource room teacher, really made me feel part of the team. They made me feel good about how I was doing as a parent. They also respected my opinion concerning behavioral interventions that they set up for Jim. They didn't look to me as having all the answers, but we all felt that if we worked together, we could figure something out." "There was one time that I really felt like the doctors almost went out of their way to make me feel stupid. Thankfully, it wasn't here. It was in Germany, when AJ was 2 and he went in the hospital for a brain stem auditory response test. I spoke good enough German, so I knew the problem was not a language barrier. They acted like I didn't need to know any of the results because I was just a mother—only educated and trained doctors knew what all those charts meant. I really had to push to get the least little bit of information. We ended up having the test done again in the American military hospital."
Skills • Action • Special needs met • Learn • Expectations • Holistic	"AJ's new teacher is really good in many ways. First of all is his experience with AJ and lots of other kids. He plans and prepares for AJ's success by developing a visual schedule that AJ needs, by talking to the kids on the bus about AJ, and by working with each of his different teachers to help them understand how to best work with AJ. I feel that if he didn't do this, AJ would not be successful in school, and I would worry constantly about how school is going." "Sometimes I get so tired of hearing people say, 'I don't know' and not offering to help find out. One of AJ's case managers told me one time, 'Well, I don't know anything about that; when you find out could you let me know?' Well, I'm happy to share information, but it would have been nice if she would have said something like, 'We all need to know about that—let me find out about it, and I'll let my colleagues and you know as soon as I do.' But I felt that I had one more thing that I had to go do now. I didn't have the time or the energy at that point, so it never got done."

Original Conceptualization

Interpersonal

Structural

Interagency

Intra-agency

Family Member/
Service Provider

Integration
Collaboration
Coordination
Cooperation

Partnership Continuum

Revised Conceptualization

Interpersonal

Structural

Interagency

Intra-agency

Family Member/
Service Provider

Figure 4.5 Original and Revised Partnership Models

Measurement Tools for Family Quality of Life Outcomes. We are following the same process to develop family quality of life tools as we are using in the partnership study (see Table 4.2 and Figure 4.6). The *Family Quality of Life Scale for Families* has comprised 10 domains—4 domains that are a function of the family unit as a whole and 6 that primarily function at the level of the impact of individual members on the family unit as a whole. The domains at the level of family unit were family interaction, daily life, parenting, and financial well-being. The domains at the individual level were emotional well-being, health, productivity, social well-being, physical environment, and advocacy. Table 4.6 identifies and briefly defines the original 10 domains, identifies the major indicators associated with each domain, and illustrates them via the Poston family.

Table 4.6
Family Quality of Life Domains, Indicators, and Poston Family Examples

Domains and Indicators	Denise's Perspectives
Family Interaction • Relationships • Communication • Roles • Interactional environment	"We have dyads in our family, but limited interaction among the three of us. AJ and Jim's relationship consists of ignoring or teasing and fighting. I would love to be able to do something as a family without the constant bickering back and forth."
Daily Family Life • Household chores • Providing care • Daily routine	"I'm stressed a little about the afternoon after-school pick-up routine. The boys' schools both get out at the same time, and they are in different locations. I have to pick Jim up and then race home to make sure I am there when AJ's bus drops him off. If I'm not there, he might not get off the bus, or he would get upset because I'm not there. I need to be able to be in two places at once."
Parenting • Teaching/guiding • Supervising • Discipline	"I try to stay consistent with expectations for the boys, but it's difficult. Jim sees that the standard is different of him than for AJ. We have chores, allowance, bedtimes, and family rules. I think it helps set the tone for how I expect them to behave. It's difficult, being a single parent, to always be consistent—they sure can wear me down!"

(table continues)

(table 4.6 continued)

Domains and Indicators	Denise's Perspectives
Financial • Basic necessities • Health care, education, & transportation costs • Extras • Sources of income • Money management/ financial assistance	"I wanted the kids to go to a specific school in town, so I had to find a house to rent in that area. It just happened to be a newer area and much more expensive than other areas in town. I found a place, but it is smaller than I wanted—I had only so much to budget for rent and had to sacrifice space for location."
Emotional Well-Being • Positive thinking • Identity • Personal harmony • Adaptability • Control • Stress management	"With AJ in the state hospital now (temporarily), how am I to define my role as mother? Although it was difficult to care for him sometimes, at least my role was clear—there was daily caring and shepherding that took place. Now I'm still confused about how to 'be'. How do I be a woman, separate from my role as Mom?"
Health • Physical • Mental • Access to health care • Strategies to promote health	"Thank goodness we are all fairly healthy physically. I don't know how I could handle everything that goes on if I were sick or had a chronic illness. For us, finding doctors is an important thing, but not critical. Our mental health is another matter. We are doing okay, but I feel that mental health services are critical to keeping me able to go on. So now, I'm 'shopping' for a counselor. No one I knew had anyone they could recommend, so I'm calling different counselors, asking first if they accept our insurance, and then trying to figure out over the phone if he or she would be a good counselor for me. I've seen two different people. Although they were good, I still feel like I need to keep looking."
Productivity • School • Work life • Leisure • Personal development • Accomplishment	"School is a challenge for Jim—he's a smart kid, but unless he has a teacher who is flexible and has a sense of humor, he can get into trouble real easily. How he does in school has a direct relationship on his self-esteem. So we work hard to do what we can to help him succeed."

(table 4.6 continued)

| Domains and Indicators	Denise's Perspectives
Social Well-Being • Relationships • Social belonging • Social support	"The biggest impact of our move on Jim was losing his friends. We are still close enough that he can see them every once in a while—but it takes a lot of effort to make that happen. He only has one friend in the new town so far. But I'm hoping he can make some friends in the neighborhood, at scouts, in church, and at school. For Jim, friendships are very important. He is really a social animal."
Physical Environment (safety, space, & comfort) • Home • School • Work • Neighborhood & community environment	"Our new home is much smaller than the one from which we just moved. This could be good news—once I get everything put away, it will be much easier to keep clean. I miss the space though. This house is bright and comfortable. I like it here and so do the kids. We were lucky to find a place in the right neighborhood (for schools), with a fenced yard for the dog, that is pretty much affordable. Now I just need to keep AJ from putting holes in the walls—during his last tantrum he broke three doors. So now I'm searching for a handyman to keep the things repaired without going through the landlord."
Advocacy • Skills • School • Health • Human service • Government benefits	"Everything having to do with 'the system' is always so difficult. I cringe when I think I'm going to have to ask someone for something out of the ordinary. I probably should do more work with the system to improve things for AJ, but I seem to have no energy to do this—what I do I do out of absolute necessity or guilt. I wish advocacy didn't depend so much on me."

PAR = participatory action research.
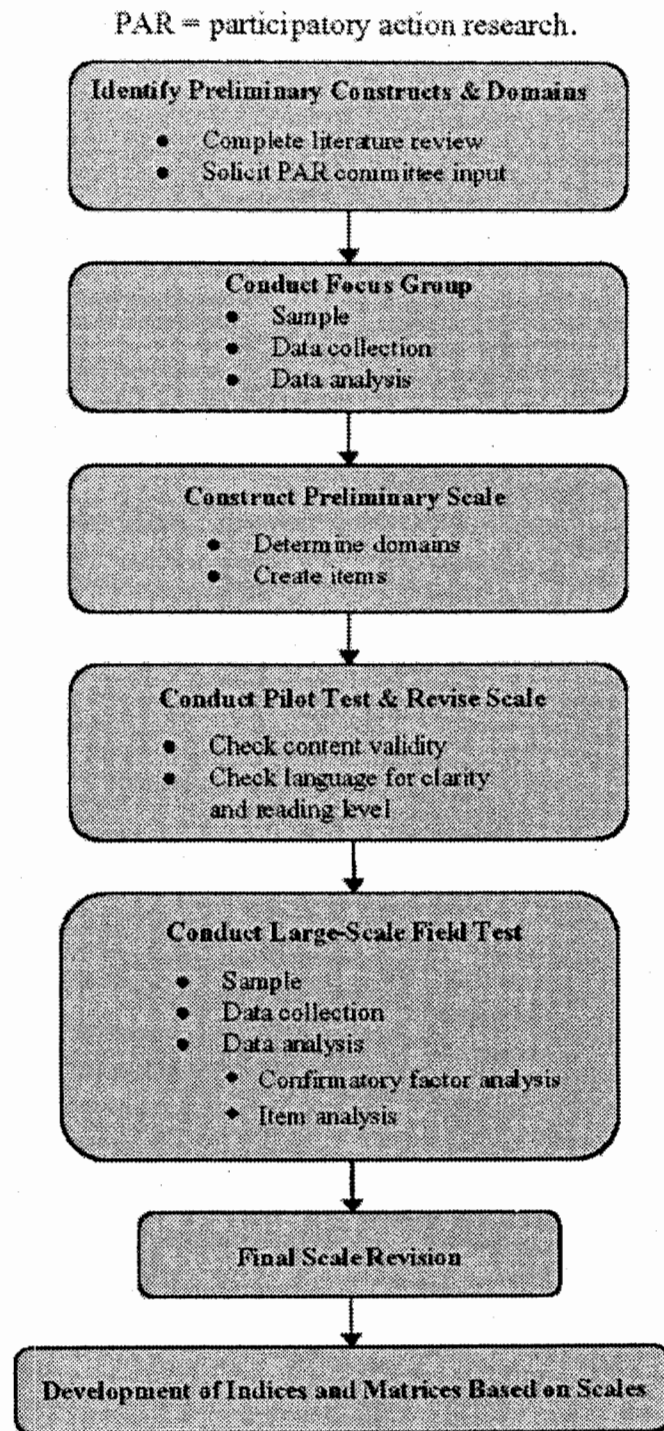
Figure 4.6. Steps in constructing family partnership and family quality of life scales, indices, and matrices.

We have field tested the scale with approximately 1,200 families of children with disabilities. In conducting the confirmatory factor analyses, we analyzed separately for family roles (e.g., mothers, fathers, individuals with a disability, and siblings). As a result of this field test, we reduced the number of family quality of life domains from 10 to 5 (Park et al., 2003): family interaction, parenting, support for the family member with a disability, family resources, and health and safety. In addition, we revised our family quality of life survey so that we included 41 different items, and we simplified the language that describes those items so that families can complete the survey more easily. In an additional analysis, we are exploring the impact of socioeconomic status, geographic location (urban, rural, suburban), lifespan stage, and possibly race or ethnicity. We also are examining different ways of aggregating the individual family member scores to attain an overall family score.
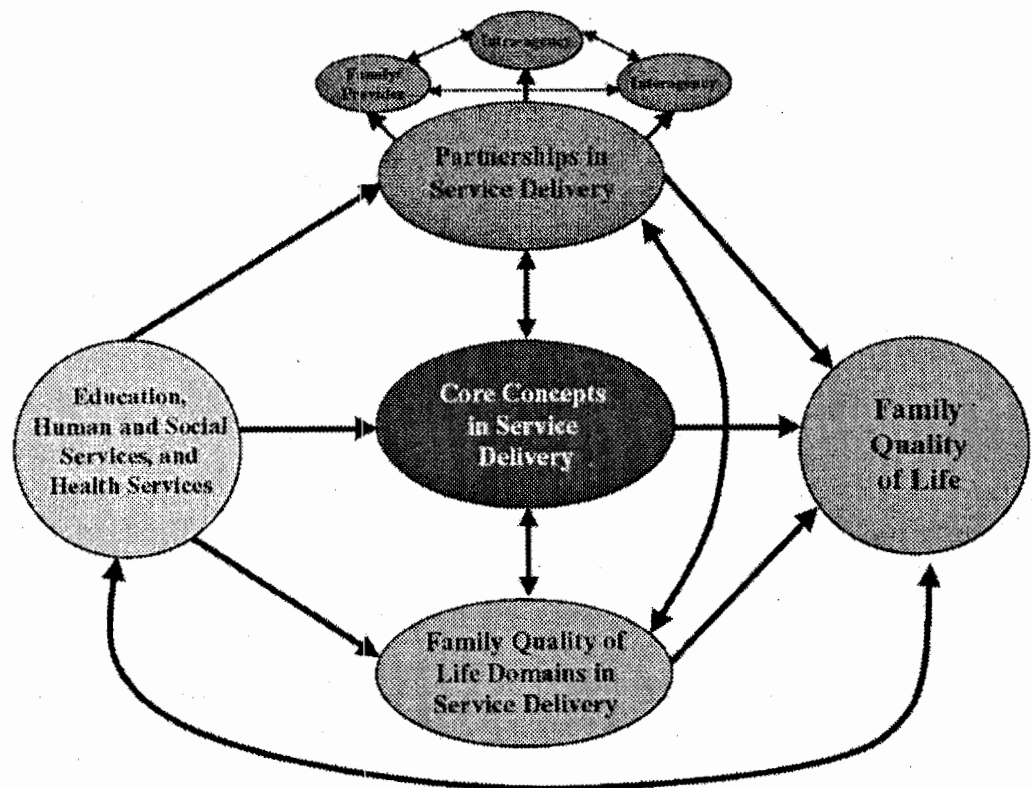
Figure 4.7. Structural model for explanatory research.

Once we develop the *Family Quality of Life Scale for Families*, we will convert it to a *Family Quality of Life Index for Families* and a *Family Quality of Life Index for Professionals*. Families and professionals will use these indices to report their perceptions of importance and satisfaction with how family quality of life domains are incorporated into service delivery.

The final measurement tool related to family quality of life is a *Family Quality of Life Domain Matrix for Policy Analysis*. This matrix will be used to assess federal and state statutes in terms of the *appropriateness* of incorporating family quality of life domains in the statutes and the *coherence* with which family quality of life domains are incorporated into the statutes. We will construct and use this matrix in a way that is similar to the way we construct and use the *Disability Policy Core Concepts Matrix for Policy Analysis*.

Overview of Programmatic Research Agenda

With the analytical framework guiding us and with these measurement tools enabling us, we are carrying out a research agenda on three levels: policy analysis, explanatory research, and program evaluation and quality enhancement.

Policy Analysis. As we explained earlier, we are developing tools for analyzing policy and practice. With the two matrices, we are analyzing federal and state statutes to determine the degree to which they incorporate one or more of the disability policy core concepts (see Table 4.3) and family quality of life domains (see Table 4.6) (H. Turnbull, Beegle, & Stowe, 2001; H. Turnbull & Stowe, 2001).

Based on that policy analysis, we are developing a Disability Policy Grade Card. This card, developed for each statute that we analyze, describes the extent to which the statute (i.e., formal policy) advances the disability policy core concepts and family quality of life domains. More important, the grade card serves as a basis for policy enhancement through the legislative route (e.g., amendments to existing statutes and enactment of new laws) and/or the executive agency route (e.g., amendments to existing regulations, promulgation of new regulations, and adoption of guidelines governing the content of competitive contracts, grants, and cooperative agreements). In providing technical assistance to federal and state policy leaders, we give priority to statutes that are deemed to be highly *appropriate* for incorporation of disability core concepts and family quality of life domains but have low *coherence*.

Explanatory Research. Using the measurement tools, we can examine statistically the relationships among the core concepts of disability policy, service provision offered through partnership arrangements, and family quality of life outcomes. Based on the analytical framework, our hypothesized structural model (see Figure 4.7) suggests that a family's perceived quality of life is positively related to the services the family receives, and that the processes through which the services are delivered (incorporation of core concepts through authorized 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 outcomes. We are testing this structural model separately for each of the three service strands of education, human and social services, and health. We are also testing it in programs that are explicitly aimed at integrating services across strands.

In addition to investigating the mediating factors of this structural model, the relationship among the various factors can also be investigated in light of the family's structure (e.g., single-parent status), 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 (Fujiura & Yamaki, 1997, 2000; LaPlante et al., 1996; Newacheck & Halfon, 1998).

Program Evaluation and Quality Enhancement. For policy analysis and explanatory research to benefit families (including children and youth with disabilities), we will be in a position to conduct thorough program evaluation and quality enhancement processes within strand-specific programs and in programs that reflect service integration. The Council on Quality and Leadership in Supports for People With Disabilities has taken a leadership role in combining principles of total quality management, reengineering, and disability state-of-art concepts (Gardner & Nudler, 1999). The Council focuses on personal outcomes for adults with developmental disabilities. We hope to extend the Council's work by focusing on outcomes for families of children and youth with disabilities, especially those families with single-parent status and lower socioeconomic status.

Research on an enhancement process should focus on increasing the incorporation of disability core concepts and family quality of life domains into services, infusing an empowering process into the family-service provider, intra-agency, and interagency partnerships, and ultimately increasing family quality of life outcomes. An appropriate methodology is a multiple- case-study design that allows for the analysis of individual cases as subunits as well as cross-case analyses designed to identify patterns (Yin, 1994). Case study methodology is a valuable means for exploring the impact and process related to quality enhancement (Campbell, 1994; Gardner & Nudler, 1999).

Implications of Our Research

In this section, we will discuss implications of our research for improving the sociopolitical context, enhancing interpersonal and organizational partnerships, and shaping a future research agenda related to enhancing family quality of life.

For Improving the Sociopolitical Context

It is axiomatic within the new paradigm that policy is an environment that affects individuals with disabilities and their families. It is also axiomatic that those who have knowledge too often are irrelevant to those who have power. On the one hand, there are the generators and transmitters of knowledge (collectively, researchers); on the other, there are politicians and legislators, bureaucrats, and advocates (collectively, policy makers). This suggests two challenges: first, to connect the researchers and policy makers to each

other and to answer the "so what?" question (now that we know something, *so, what* do we do with that knowledge?), and, second, to assure that research is both disseminated and used. Beyond mere dissemination and utilization, there is also the challenge of solidifying good policy and practice and then assuring that what is solidified does not become fossilized. To these ends, several strategies are apposite (H. Turnbull & A. Turnbull, 1996):

- create model statutes, regulations, and practice protocols;
- create teaching and technical assistance modules that contain the model statutes, regulations, and practice protocols and that are easily adaptable to multiple formats (e.g., print, voice, e-mail, and Internet);
- secure the use of the models and modules by state and local governmental policy leaders and their national and state associations (e.g., National Governors Association, National Conference of State Legislatures, National Association of State Directors of Special Education);
- secure the use of the models and modules by institutions of higher education as they carry out preservice and in-service (continuing) education of professionals and consumers;
- secure the use of the models and modules by advocacy organizations;
- persuade "insiders" to adopt the models, for it is always the case that a few members of a legislature, of an executive cabinet, or of a staff are the "play makers" in making or carrying out good policy.

For Improving the Service Delivery System

We have identified and measured the aspects of interpersonal relationships among the partners working with a family—those aspects that foster positive partnerships among members of the team and among professionals and family members. Assuming that our measures are validated, we will move both forward and backward in our analytical framework. That is, we will address several questions:

- What are the potential antecedents of positive partnerships? What are the administrative decisions, organizational procedures, and policies that nurture positive interpersonal partnerships among families, intra-agency and interagency team members? Our current work is focusing on identifying structures that we may consider "candidates" for having impacts on positive partnerships.
- Do these targeted structures and policies indeed have an impact on interpersonal partnerships, as we are measuring it? This will require a series of research studies, ranging perhaps from intervention

research to identification and measurement of exemplary programs across the country.

- Do positive partnerships also have a positive impact on family quality of life?

In general, our vision for the most direct application of this work is to provide policy makers, administrators, professionals and families with the ability to make *targeted* decisions and policy changes. We expect to develop self-assessment tools that will enable agencies and communities to identify strengths and challenges in the quality of their partnerships at all levels, use the tools to diagnose or identify those structural aspects of their organizations that require modification to improve partnerships, and measure the effectiveness of any innovations or changes made in their partnerships.

For a Future Research Agenda

One challenge in family quality of life research is to discover how to aggregate data to address the family as the unit of analysis. Typically research uses only mothers or, in far fewer cases, fathers as the unit of analysis when purporting to measure family perspectives. When we analyze our field-test data, we will investigate various ways to calculate a "family score" or a "family profile" from the scales that are filled out by several family members. Simple addition will not be the best representation of the family score, because the nature and degree of different family members' impact on the overall family is not the same. Different cultures have alternative interpretations of appropriate roles and influence of various family members (Lynch & Hanson, 1998); thus the aggregation of family scores must be highly culturally sensitive. Our challenge is to evaluate the potential benefits and drawbacks of analyzing scores separately for each individual family member compared to analyzing scores that aggregate family data.

Regardless of whether scores are individually reported or are aggregated, our participatory action research partners have consistently warned us that they fear that our scale might be misused by agencies to judge families as pathological or used as the basis of withholding services and supports from families. Thus we are committed to ensuring that this scale and others will not be used to harm families in any way. Instead, we will stress that our family quality of life tools can be used to measure the extent to which services meet the expectations of families; this is consistent with a new paradigm of "fixing" multiple environments. The old paradigm only assesses families and then uses scores to determine how they might be "fixed."

Future research can also create a database that accumulates and aggregates the scale results from diverse families. Policy makers can use this database to gain information about the impact of policies on the quality of life of families of children with disabilities according to various family characteristics

(e.g., socioeconomic status, ethnicity, geography, or the severity and type of the family member's disability). Furthermore, this large database will enable researchers to establish patterns of family responses that are impossible to establish with smaller, localized samples. Jim Gardner at the Council on Quality and Leadership in Supports for People With Developmental Disabilities has created a model of such a database related to quality of life outcomes for individuals with developmental disabilities.[1]

In the future, researchers will be able to use the *Family Quality of Life Scale for Families* to measure families' satisfaction with their quality of life. This scale can be used in several ways:

- as a *planning tool* to establish individually tailored service or supports plans for families by determining the family quality of life indicators that are important to them and the extent of their satisfaction on those indicators;

- as a *strengths assessment* by identifying a family's individual, collective, and environmental assets, which will establish the direction and means of supports and services;

- as a *longitudinal evaluation* of service delivery and policy reform, since the ultimate outcome of changes in service delivery and policy would be enhanced family quality of life.

Before the *Family Quality of Life Scale for Families* is used as a planning tool, we need to explicate the issues that families may want to consider related to each of the domains. We envision having a supplemental checklist for each domain. The checklist will enable families to engage in individual and family reflection about priorities, possibilities, and the nature of the services and supports that would be most helpful to them. The development of these domain-specific checklists is one of our major research agendas.

A Year Later: A Future Day in the Life of the Poston Family

AJ has learned to wake on his own with help from an alarm clock. Our GAP group recommended the clock as a way to help AJ be more independent and make things run more smoothly in the mornings. One of his personal assistants started coming at 6:30 A.M. to help him learn to get up with the alarm. Now I don't have to cajole him out of bed in the morning.

Both boys are doing well in school. Jim has a lot of homework, but we don't argue about it as much anymore. I think the counseling has

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1.   See the website of Council on Quality and Leadership in Supports for People With Developmental Disabilities, National Center on Outcomes Resources: http://www.the-council.org

really helped him learn to communicate his feelings and take more responsibility for his own actions. We finally got Jim matched with a "Big Brother." Having a male role model in his life has been good for him. He has so many friends at school, scouts, and church that I can hardly keep up with his schedule. It has made my role as taxi mom harder, but he is so happy.

AJ is also blossoming at school. He goes to five different classes. The school staff has done an excellent job of modifying the curriculum so that he is learning the same subject matter as the other kids, but geared to his level and learning style. He is participating in a lot of after- school extracurricular activities with the support of his teacher and personal assistants. His teacher was instrumental in training the people whom AJ's case manager recruited. They all work together now, applying the same behavioral supports. The new medication helps take the edge off his impulsiveness. We haven't seen any side effects either, which is what I was so worried about. We have also been concentrating on how to deescalate the aggression once it starts.

I feel that life is really moving along smoothly. I finally completed my studies and received my doctorate. It sure feels good to have reached that goal in my life. AJ's service coordinator has taken a huge role in coordinating and monitoring the various services and supports for AJ. I am still very much involved, but now I'm able to focus more time on Jim and myself. I feel much less stressed, so I am a much more pleasant person to be around. With the supports that AJ has, we have actually been able to do things as a family now. We went to a movie last night and plan to go to the church picnic this Sunday. One of AJ's personal assistants joins in whatever we are doing; I guess our family has grown a little! That's okay, because they are all nice people and fit in really well with the three of us.

The new HCBS Medicaid funding policy took effect a few months ago. The proposed policy could have been disastrous for us because of the way the funds were to be allocated. But a group from Lawrence—people with disabilities, family members, and service providers—got together with people from other communities and mounted a campaign at the state level that forced a change in the proposed policy. We had to cut back a little on the amount we receive, but not as much as it would have been if we had not been advocates. The whole experience was good for me. I met some new

people and feel like I really helped make a difference, not just for our family, but also for many other families.

The Lawrence group that worked on the HCBS funding issue has gotten back together and focused on a new project. We are trying to start a one-stop family support coalition. If we had had something like this when our family first moved to Lawrence, our transition would have been so much easier. We are talking to families throughout the community about what they think would be beneficial to their families. It seems that most people want neighborhood-based, family-centered and family-directed "centers" that are independent of the existing provider systems but know about all the available services and supports in our community. We hope to make that happen within the next 6 months.

Denise Poston

Epilogue

One must never underestimate the power of an idea whose time has come, the power of inertia, and the complexities of the policy environment. Family quality of life enhancement will inevitably be met by resistance to change. For that reason, researchers must embrace the complexities of all environments, understanding them and participating in them as participatory researchers. As the Chorus in Shakespeare's *Henry V* foretold in advance of Henry engaging in the Battle of Agincourt, combatants must "assume the port of Mars." Here lies an apt analogy: It is not enough to be a researcher, one must also be a warrior in diligent pursuit of making a difference. Knowledge is power only if the knowledgeable act powerfully.

Finally, because what we think we know changes as we conduct research, the challenge is to solidify policy and service delivery based on what we think we know now and then to critically assess innovations, lest they—and our research and knowledge—become fossilized. Winning the Battle of Agincourt was only the first of Henry's challenges; winning the peace thereafter was his second, and hence his marriage to Catherine of Aragon—truly an international metaphor for an international book such as this on family quality of life research.

Postscript: February 2002

Under the heading "General Trends," there have been a few changes. The text under "Demographics and Economics" should be changed to reflect the fact that a national recession is in progress, having begun in the fall of 2000.

The recession drastically increased the number of un- and underemployed individuals, and it is likely that among those who are now in those categories are many with disabilities. Likewise, the recession seriously impaired state governments' abilities to fund human and social service programs.

Also, the "9/11" incidents—the terrorists' destruction of the two World Trade Center buildings, the partial destruction of the Pentagon, and the failed attempt to further destroy symbols of American dominion—have skewed the federal and state governments' budgets to such a degree that the country's fiscal priorities no longer accommodate human services except in response to the "9/11" priorities.

Under the heading "Politics: Moderation and the New Federalism," it should be noted that the Supreme Court continues to eviscerate federal disability policy; Congress is being guided by a powerful right wing–ultraconservative leadership in the House of Representatives; and the omens for disability issues are dark.

Under the heading "Disability Trends," the consolidation of rights is still a priority, especially considering the attack on Individuals With Disabilities Education Act that has been launched by conservatives who seem to know little about disability (see Finn, Rotherham, & Hokanson, 2001).

Finally, for a complete review (as of fall 2001) of the Beach Center's work on core concepts and disability policy, see the series of articles published in *Journal of Disability Policy Studies 12*(3) (H. Turnbull, Beegle, & Stowe, 2001; H. Turnbull & Stowe, 2001).

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