



WELL-BEING AND SUSTAINABILITY OF DAILY ROUTINES

Families with Children with Disabilities in the United States

Thomas S. Weisner

Introduction

Parents everywhere have a common project: to construct a social ecology that balances what they want for themselves and their family, with what is possible given their circumstances. This project involves *sustaining* a daily routine of life. Sustainability is a holistic conceptualization of how families are doing with respect to this project. Ecological-cultural (hereafter *ecocultural*) theory suggests that sustaining a daily routine is a universal adaptive problem for all families (Whiting 1976, 1980; Munroe, Munroe, and Whiting 1981; Whiting and Edwards 1988; Weisner 1984, 1993). Ecocultural family theory uses Super and Harkness' notion of a developmental niche for the child (1980, 1986), extended to the study of the family and ecological context (Weisner 1997). Well-being is created and experienced within this cultural learning environment.

Assessing this project for families and in research in human development requires that we include the goals of parents in a community, since those goals matter for what is considered normative, and what is the appropriate moral direction for family life and development (LeVine, Miller, and West 1988). Yet assessments of families and children are too often based on the implicit or explicit adoption by researchers of goals for families and for children that come from the United States and Western Europe. For example, American parents worry if their children are not talking early; parents conflate verbal skills with intelligence, and may seek help for this developmental "delay." The goal of academic achievement and success translates into parental concerns over one milestone, but not others.

Signs of nurturance and interpersonal obligation in a young child might make many American parents concerned over insufficient independence in their child, rather than seen as a positive sign of pre-

cious interdependence. Indeed autonomy, or the individuation part of all development, is commonly confounded with egoistic independence. Autonomy includes volitional action and agency in the service of goals (including relational and interdependent action). The goal of social intelligence and empathy in children is altogether more important in many communities than it is in the US. Such differences in the interpretations of family and child development illustrate that diverse goals and beliefs regarding what should mark a culturally constituted successful social career influence what is viewed as positive, normative development. Children are learning to be appropriate social persons, and individual, discrete measures of ability taken out of context do not capture this project. LeVine (2003) conceptualizes enculturation as the acquisition of "local idioms" based on goals and practices within diverse local populations. These local idioms (meanings, beliefs, scripts for action, shared practices, ways of organizing everyday routines of life) matter for how families sustain family life and how they conceive of and socialize for well-being in their local cultural learning environment.

What is the connection between sustainability of a meaningful routine of daily life, and well-being? Sustainability of life in a family or community grounds well-being in everyday activities, includes the goals and moral direction of life, and provides a definition that can apply cross-culturally. More sustainable routines are undoubtedly associated with well-being in that community. Well-being, in ecocultural theory, is *engaged participation in everyday cultural activities that are deemed desirable by a community, and the psychological experiences produced by such engagement*.

What constitutes a more sustainable routine of daily life that enhances well-being? The image of contexts, activities, and practices as stepping stones along a path is a useful one. Think of a daily routine as a linked set of these activities that we "step into," or engage with, as we move through the day, week, month, and years. The path exists in some local community, and intersects with many other paths. Sustainability, like well-being as I define it, must always be understood as a project somewhere in a cultural learning environment, in some particular community with its constellation of goals and local constraints and opportunities.

Sustaining a daily routine involves four processes (Weisner 2002; Weisner et al. 2005): fitting the routine to family resources, balancing varied family interests and conflicts, meaningfulness of family activities with respect to goals and values, and providing stability and predictability of the daily routine. Routines that have better resource fit, less conflict, more balance, more meaningfulness, and enough predict-

ability are posited to be better for families, and so to provide greater well-being for those participating in them. Sustainability in the life of a family and children is better for a child's development and for parenting. To the extent that these features of a sustainable routine can be assessed and understood in a community, these data would constitute evidence for a reliable and valid contextual universal for comparing families and communities across cultures.

This is the conceptual and empirical connection between sustainability and the topic of this volume, well-being. Well-being, like sustainability, is an ongoing project, not a one-time end point. It is contextual, embedded in an everyday routine of life, and so part of some local social context with its local idioms. It includes both the local resources and ecology of the family and community, and the goals, values, and meanings that the community affords and people bring to their practices. For this reason, understanding well-being requires contextual and ethnographic data and methods, just as sustainability does.

The unit of analysis (local practices and activities) of both sustainability and well-being is very familiar and congenial to ethnographic methods, as well as to other methods anthropologists use, such as interviews, questionnaires, individual assessments, and systematic behavior observations. Activities have features that recur and structure them, including a *script* for normative conduct; *goals and values* organizing the meaning and direction of the activity; a *task* and functional outcomes the activity is there to accomplish; *people* and their relationships that are present in the activity; the motivations and feelings that people have in the setting that influence their *engagement* in it; and the *resources* needed to constitute the activity and make it happen (Cole 1996; Weisner 2002). Sustainability, because it defines a higher-quality family daily routine (which consists of activities prevalent in a community) should enhance well-being.

Sustainability of family routines differs from stress, coping, and similar challenges, although those familiar constructs are also certainly involved in sustaining a family daily routine. The stress and coping models begin with an unusual, difficult perturbation that is a challenge or threat (or at least potentially so), and then look for the responses of individuals or families to those perturbations. Resilience or adaptation is the successful response to such threats. Sustainability, however, captures another, more enduring project: juggling ongoing demands in the service of meeting long-term goals (Gallimore, Bernheimer, and Weisner 1999). Sustainability focuses on the everyday accommodations made in a local context that keep life going, that is, keep alive the daily routines expectable and meaningful in that community. Sustaining a daily routine can be positive as well as negative at times in terms of

one's affective experience and effort. Accommodations are not necessarily stressful or the result of coping with difficulty, and can be rather unremarkable and mundane to those doing them—yet no less sustaining and promotive of well-being, often because of this everyday, implicit aspect.

Cultural goals and meanings do not simply float in a collective community's beliefs, and then—somehow—lead to motivated actions that can enhance well-being. Cultural models include scripts for action in settings. These scripts and the settings they are activated in then give cultural models their "directive force" (Quinn and Holland 1987; D'Andrade and Strauss 1992) by shaping action and thought. There is a script for eating a meal together, attending a class, visiting grandparents, or caring for a sibling. Sustaining a daily routine that is meaningful with respect to at least some of a person's goals includes enacting a script for these activities, which directs behavior. Enacting these scripts are a part of what makes life worth living.

Sustainability and well-being foreground the interconnection between mind and context, and emphasize the social character of mind. Being in a local context produces psychological experiences in individual minds. It is also of course true that individual minds vary in the ways they appraise and experience a context. The point for thinking about well-being in this way is that the psychological experiences are not only *individual* intrapsychic experiences; they are a product of social context and the "social mind" as well.

Well-being and sustainability are contextual universals: the features of sustainability should enhance well-being in any community, but the local meanings and contexts of that community are a part of measuring and understanding well-being. Cultural and ethnographic studies of well-being thus can provide evidence for universals as well as differences and particulars.

Connections of Sustainability and Well-Being to Chapters in This Volume

Although Thin, in chapter 1, suggests that anthropology has focused too little on well-being and positive affects and too much on adaptation, relativism, or ill-being, students of culture and human development in anthropology have given much more attention to positive child development and well-being than perhaps have other fields in anthropology. The comparative and analytical attention to well-being certainly deserves renewed attention in anthropology, but Thin underestimates the field of *neurological anthropology* and the study of childhood and

parenting as a rich, extensive, and long-standing research area interested in these topics (LeVine 2007). If there is one finding that is central in the field of culture and human development, it is that communities vary in what good development is, and in the ways parents and communities set children on those desired pathways. Anthropologists also recognize the universal requirements of maturation and care as important everywhere. Add the ethnographic attention to local idioms for care and parenting in these diverse cultural learning environments, ecocultural context, and everyday routines of life for children and parents, and it is evident that the study of child and family well-being in this field of anthropology is central.

Sustainability provides a link—a “translational definition”—connecting many of the anthropological perspectives on well-being featured in this volume (Weisner 1998). The essays in this volume develop, in their own ways, the features of sustainability (resources and their match to goals and values people feel they can attain, meaning and emotional experience and engagement with community practices, the benefits of low conflict and social relationships, and predictability and adaptability).

Mathews and Izquierdo emphasize in their conclusion health, sociality, existential, and structural bases of well-being. They and many other authors emphasize the importance of the experience and conceptions of well-being in particular local contexts. Izquierdo's rich ethnographic understanding of Matsigenka well-being (chapter 3) contrasts physiological health indicators (which show improvement) with the sense of community fragmentation and existential crisis in the face of the absence of a meaningful account of why distressful events are happening (all getting worse). The resources and wealth from the presence of outsiders and natural gas extraction create social conflicts that reduce well-being.

Several papers show the importance of cultural meaning and local idioms for well-being. Clark, in chapter 9, focuses on bathing in Japan, and Clark's pleasure context (settings, activities, and meanings of seeking a positive experienced state) is a rich example of a practice that enhances well-being. Mathews in chapter 8 emphasizes the meaning system of what makes life worth living in Japan, Hong Kong, and the US, as a key to the existential meanings of personal well-being. Cultural framing, social negotiations, and institutional channels all are key dimensions for creating and accounting for well-being.

Derné in chapter 6 focuses on subjective experience and the internal state of mind crucial to well-being among middle-class, upper-caste Hindu men; love itself follows from social expectations about marriage as being based on a fit with extended family life. Nurturing

others (as contrasted with individual achievement as a cultural goal and self-ideal) engages experiences of well-being for these men. A cultural model leads to a script for action in this community, which in turn leads to well-being as locally defined. Heil in chapter 4 also finds that well-being in an Australian Aboriginal community involves a person's capacity to make and meet the requirements of kin-related, socially engaged responsiveness, rather than individualized physical or mental states. Adelson in chapter 5 describes the historic identification of Eastern Cree well-being with connections to their ancestral land and the cultural and familial meanings that flowed from that. Hollan in chapter 10 describes individual selfscapes, in which well-being is a subjective, temporally and spatially dependent experience. Selfscapes emerge out of a constant mapping of a person's cultural representations of past experiences onto the current culturally constituted world.

Adaptive potential is the key organizing concept in Colby's model (chapter 2); sustaining a daily routine is also an adaptive and functional project. Jankowiak in chapter 7 proposes a connection between well-being, social engagement, and a sense of personal choice: if people feel some sense of control over resources and social relationships, and have at least some of the resources to attain some of those chosen goals, they are going to feel a greater sense of well-being. Jankowiak's model emphasizes the fit between engagement and well-being: activities in a community that are not deemed desirable (or around which there is ambivalence and conflict), such as the Chinese communist-era settings without a sense of control, will not have high engagement and so will have at best mixed effects on positive well-being.

Other Indicators of Well-Being

As Colby, Thin, Jankowiak, Mathews, and Izquierdo point out, the social sciences are hardly unaware of well-being. There are extensive and well-researched empirical indices of life satisfaction, life quality, and well-being already available. These other indicators of well-being are not likely to be replaced by anthropological ones, nor should they be. There are good indicators available for child and family well-being, for instance. Brown (1997) reviews the major indicators used by the United States federal statistical system for assessing child well-being. None are existential or deeply contextual, nor do they include the moral dimension and meanings important to anthropologists (except insofar as they assume that the current United States provides implicitly universal standards), but many surely matter for well-being. The indicators

include child health, education, economic security, family and demographic characteristics (race, immigration, social isolation, household, and neighborhood), and social development and problem behavior indicators (such as having friends, life goals, and the universally negative consequences of chronic aggression and violence).

UNICEF (1997) collects and publishes indices on children's well-being as well. Their list includes mortality, adult literacy, GNP, nutrition, public health, education, demographic indicators (death rates, life expectancy), economic indicators, and status of women, as well as the rates of progress on each of these indicators. Bornstein et al. (2003) focus on positive development: resilience, successful adaptation, happiness, good health, and similar indicators, measured across the life span. Sutcliffe (2001) recasts many such indicators of life quality and well-being. He illuminates the stark and in some cases growing global inequality between nation-states as well as inequality among subgroups within a nation-state. Vlemingx and Smeeding (2001) provide indicators for the developed world that also show clear differences across modern nation-states. Their work provides strong evidence that the developed world is far from homogenous on a variety of indicators of life quality and well-being, and that we need to be cautious and specific when making global comparisons between the developed and the rest of the world on well-being, using conventional indicators. Anthropological perspectives on well-being will certainly add to the evidence for the need for pluralism in measuring and comparing well-being around the world.

Ben-Arieh and Goerge (2005) have assembled a rich collection of indicators of children's well-being. Their book focuses on measurement and design of well-being research, and on using social indicators like well-being to affect child and family policy. A web site, www.childindicators.com, extends the use of well-being measures in the service of effective policy and practice, and a society, the International Society for Child Indicators, has been founded to further this goal.

Many of these indicators of well-being rely on *individual* indicators and then aggregate and summarize them for nations or regions. This can lead to reifying the averages across individuals and then claiming family, community, or cultural well-being at the group level, absent evidence regarding shared meanings and practices which in fact have not been collected at family, community, or cultural levels of analysis. This is a point made in many chapters in our volume. It is not that both individual and contextual indicators are not relevant, but rather that indicators at only individual levels are insufficient.

Well-being is about a person-in-context. Context or setting-level indicators are important for assessing and understanding well-being, along

with individual measures. Earls and Carlson (1995) have called for the incorporation of the experiences of parents and children in local cultural context into family and child well-being work. Sustainability of family routines is a general, meaningful outcome for families that meet this criterion.

Sustainability complements other indices of well-being; it does not replace them. Sustainability and the other anthropologically informed ideas in this volume are conceptually different and add value to existing indices of quality of life and well-being. To illustrate the added value of sustainability, my collaborators and I tested whether sustainability in fact adds explanatory value alongside other indicators (both individual and context-level) of well-being and life quality. The study was of families with a child with a disability in Los Angeles. The evidence shows that a holistic assessment of sustainability in families does add both descriptive and explanatory value.

Families with Children with Disabilities in the United States

Just as for general indicators of well-being and quality of life, there already are many useful measures of well-being specific to families and children with disabilities. Hughes and Hwang (1996), for example, offer an extensive literature review of fifteen dimensions of life quality for persons with disabilities for which there are at least some validated measures and consensus within that research field (Table 11.1). These dimensions are relevant not only to individuals with disabilities and their families, but much more broadly as well. Further, these indicators include, at least indirectly, dimensions related to more existential perspectives on well-being. Many items on the list are applicable to people with disabilities cross-culturally as well, though only with the appropriate modifications, local meanings, and the addition perhaps of other indicators that matter in varied local communities (Ingstad and Whyte 1995; Skinner and Weisner 2007). I turn now to an empirical example of the use of sustainability as a holistic assessment for understanding well-being, in concert with other measures.

Families with Children with Disabilities: The CHILD Project Sample

A cohort of 102 Euro-American families with delayed children aged three to four years old was recruited into a longitudinal study in 1985–

Table 11.1 Fifteen Dimensions (Consensus Literature Review) of Quality of Life (General and for Persons with Disabilities) (Hughes and Hwang 1996)

Social relationships and interaction (friendship, responsibility, interdependence, etc.)
Psychological well-being and personal satisfaction
Employment (skills, satisfaction, characteristics, etc.)
Self-determination, autonomy, and personal choice
Recreation and leisure
Personal competence, community adjustment, and independent living skills
Residential environment
Community integration
Normalization
Support services received
Individual and demographic indicators (income, initiative, access to transportation, etc.)
Personal development and fulfillment
Social acceptance, social status, and ecological fit
Physical and material well-being
Civic responsibility (voting, etc.)

86 in Los Angeles, California. This is the CHILD Project sample (Gallimore et al. 1989). Parents were primarily in their early to mid-thirties when we first contacted them. Twelve percent were single mothers (due to divorce, separation, widowhood, or having never married) or in a variety of other residential and marital circumstances (e.g., living with parents). About 25 percent of the mothers were employed full-time, and families ranged from below poverty level in a number of families, to a family with income over \$150,000 a year. (Further details concerning the sample, recruitment, and attrition (9 percent) are available in Gallimore et al. 1996).

Developmental Delay

Each family in our sample has a child who had been judged to be "developmentally delayed" by a professional or an agency. *Developmental delay* is a term of relatively recent vintage and lacks definitional specificity (Bernheimer and Keogh 1986). It is essentially a nonspecific "clinical" term with less ominous overtones for the future than "retarded" or

"handicapped." There is considerable diagnostic ambiguity and change in diagnosis (Bernheimer and Keogh 1988; Bernheimer, Keogh, and Coots 1993).¹ Children with known genetic abnormalities were excluded from the sample because we wanted to focus on families where the future prognosis was ambiguous and uncertain. To focus the sample further, children whose delays were associated with either known prenatal alcohol or drug usage or with postnatal neglect or abuse were excluded (Bernheimer and Keogh 1986, 1982; Bernheimer, Keogh, and Coots 1993; Gallimore et al. 1996). In addition to standardized assessments on all children, we adopted a construct parents frequently used in their conversations with us: child hassle. "Hassle" is not pejorative in parents' understanding, but rather an everyday ethnopsychological term, a key word (Wierzbicka 1997) used by many parents to describe their experiences. "Hassle" describes not only the child's behavioral, medical, and socioemotional difficulties but also *the effects of those difficulties on the family routine*. Higher hassle children displayed behavior problems that were troubling to families because they had a significant impact on the daily routine.²

Assessment of Family Sustainability and Ecocultural Context

Sample families were visited by a trained interviewer/fieldworker at child ages 3, 7, 11, 13 and 16. These fieldworkers conducted semistructured interviews with the parents, the Ecocultural Family Interview (EFI); each interview lasted from one to three hours. Parents were encouraged to "tell their story" about their child and about how they were or were not adapting their family routine, and in response to what or whom (Bernheimer and Weisner 2007). There were no false negatives; if parents did not bring up topics, we used probes that carefully covered standard ecocultural domains (resources, supports, child services, siblings, work schedules, goals, religious beliefs, etc.). Each family also completed a questionnaire covering standard demographic information and socioeconomic status characteristics of the family. Field notes also were compiled for each family. (For additional information on the various methods used in the study, see Gallimore et al. 1993; Gallimore et al. 1996; Nihira, Weisner, and Bernheimer 1994; Weisner, Matheson, and Bernheimer 1996.)

Our fieldwork staff held a series of meetings to discuss, case by case, the nature of sustainability and well-being across the families. Qualitative assessment of each family required *contextual* knowledge about each family as well as across families; *depth* of understanding; *breadth* of knowledge about the family; and *accuracy* and *precision* about what fea-

tures (such as material and social resources, family goals, or the child's behavioral problems) actually look and feel like in the context of everyday family life (Becker 1996; Weisner 1996). We attempted to develop specific indicators that would differentiate what we knew of family strengths and weaknesses within the overall framework of ecocultural theory. The typology we eventually developed emerged from dynamic discussions closely related to our comprehensive knowledge of the families and children. Fieldworkers and interviewers carefully reviewed each family, using the four criteria for assessing a daily routine (ecological and resource fit, balanced interests and conflicts, meaningfulness, and stability/predictability). Assessments were made at child ages 3, 7, 11, and 13. We also summarized the resources and constraints facing families using three indicators: socioeconomic status and resources, the family workload for accommodating to the child with disabilities, and the amount and nature of social support and connections for the family (Nihira, Weisner, and Bernheimer 1994; Weisner 1993). Fieldworkers doing assessments had no knowledge of test scores, scores on other family assessment measures, or any of the quantitative measures of family or child status.

Quality of Life

We administered the "Quality of Life Scale" (QOL) (Olson and Barnes 1982) to parents when children were age thirteen. This scale includes forty items that define twelve factors: health, marriage and family life, friends, extended family, home, education, time, religion, employment, financial well-being, impact of mass media, neighborhood, and community. Respondents are asked to indicate their satisfaction on each item using a 5-point scale, with 1 = dissatisfied and 5 = extremely satisfied.³

Sustainability Adds Value and Understanding

So, we have a suite of measures that all are implicated in one way or another, at least conceptually and often empirically, with understandings of well-being for children and families. This suite of measures includes the qualitative, holistic assessment of sustainability. I will briefly summarize four patterns of sustainability across families, and then consider the relationships between sustainability and some of these other measures. For example, would our qualitative construct of sustainability and well-being add value to a very comprehensive and widely used standard assessment tool such as QOL? Would the cognitive developmental assessments of each child predict sustainability?

Patterns of Family Sustainability

We identified families from low to high sustainability (Weisner et al. 2005). *Multiply Troubled* families are easy to recognize at the low sustainability end. These families led chaotic, precarious lives: few and uncertain resources, very little stability in their routines, a lot of conflict, and the lowest experience of life meeting their goals in meaningful ways. Parents sometimes had personal problems (alcoholism, mental illness, physical health) and felt overwhelmed. Their children were high hassle and more often than not had multiple problems. Fortunately, at least in our sample, there were no more than 8 percent of families in this category across our four visits. Unfortunately, there was little change over time in the low sustainability and well-being of these families.

The following case exemplifies the difficulties these families faced:⁴

At the age 11 visit, Carolyn was a single parent, living with her son Max in a tiny apartment with no outside play space. She was still employed as a veterinarian's assistant, making \$20,000 a year. She was unable to afford health insurance, but made too much money to qualify for AFDC. In addition, she was denied help from SSI because Max did not fit their eligibility criteria. His only diagnosis was "mild mental retardation." But according to Carolyn, "his behavior is so bad I can't stand being around him." His speech was largely unintelligible, and he was unable to get along with other children in or out of school.

Carolyn had no one she could count on for help. Her mother lived nearby, but was embarrassed by her grandson, and so Carolyn refused to ask her for help. Her neighbors were unwilling to watch Max because of his behavior problems. Carolyn disapproved of them anyway—they were too rowdy, always playing loud music. The only person who helped occasionally was Carolyn's sister, who took him once in a while. Recently Carolyn's schedule was changed from Monday thru Friday to Tuesday through Saturday. She worries about being able to keep her job because of the childcare problems.

Carolyn was pessimistic about the future. She felt the school was either unwilling or unable to teach Max anything, and she worried that the time would come when it was too late. She described herself and her son as hapless victims of an uncaring bureaucracy. When asked what she did when she felt overwhelmed, she responded, "I have to keep going. I'm by myself."

The next group, *Vulnerable but Struggling* families were "hanging on." Some 9–17 percent of families fell into this group. Parents talked about just enduring, being slow and steady, and taking things as they come. More of these parents were religious; many said that God has given them both a burden and an opportunity and they are a part of His

plan (Weisner, Beizer, and Stolze 1991). Their goals and meaningfulness sometimes were strengths for them in spite of their struggles. Most had too few resources to reliably make ends meet, relatively few outside contacts, and conflicts among family members.

Improving/Resilient families were from 25–32 percent of the sample over time, and struggled as well. Things were not easy. These families had as good a fit between the resources and demands of their ecology as the *High Sustainability* group described below, but were likely to be dissatisfied with the often poor balance and greater conflict among different family members' goals, and the sometimes lower meaningfulness of their routines. Often the dissatisfaction could be traced in part to the hassle and problems presented by the child. One mother described her family's struggles to meet the needs of all family members—the two parents, the eleven-year-old child with delays, and a two-year-old:

We've had a man coming to our house every week who's a psychologist and who is a behavioral specialist, and Pete isn't having any unusual behavior; he's really very normal behaviorally, but we were having such a hard time in our household trying to juggle him, how much attention he gets, how much attention for our daughter, each other, because we have very little time together. We were really having a hard time ... my husband and I were just really locking horns over a lot of issues.

In spite of her statement that her son was "normal behaviorally," this mother described considerable aggression from Pete to his younger sibling. Her husband's availability also had become more limited recently; he had become extremely involved in Regional Center politics, in part as a strategy for increasing their knowledge about available services:

My husband and I ... have tried so hard to find every resource possible. ... I mean almost obsessively so, he finally decided that he would just get on the board of Tri-County. We found someone who invited him to join the board. He is now on three committees and the head of one of them and very much in charge up there.

While they welcomed the additional information they gained from his activities, they were not satisfied with their family life—too much of their energy was going towards Pete, to the detriment of other family members.

Stable/Sustainable families (about 40–50 percent of the sample), with the highest sustainability scores at age eleven, have children with the lowest behavioral, medical, and communication hassle scores for any of the four groups and the fewest number of reported child problems. Jim and Ann Turner, for example, have high family sustainability and well-being. Their daughter Tori has been diagnosed with mild cerebral

palsy and ADD. Though Tori has some significant disabilities, Ann does not experience these as leading to significant hassle, either behavioral, medical, or in communication, and reports relatively few child problems, and so she (as well as Jim, by Ann's report) feels that their daily routine is reasonably stable by the time Tori reaches age eleven:

At the time of the 11-year visit, Jim and Ann reported that things were, for the most part, running smoothly. They had recently moved to a new neighborhood with more children, further away from traffic, with a large front and back yard. Anne was currently a full time homemaker, and Jim had recently returned to school to obtain his MBA, attending classes three nights a week and Saturday mornings. He continued to work full time for the phone company. Even with Jim's schedule, the Turners continued to maintain "family times." They made it a point to sit down 2–3 times a week to play a game with the children, 10-year old Tori and 13-year old Jack, or to watch a movie selected by the children. On Saturdays after his class, Jim usually worked out in the yard and the kids worked with him, giving Ann the opportunity to clean house, do laundry, etc. Every Sunday, after attending church as a family, they spent the afternoon and evening with the paternal grandparents. While Jim's schedule did cut down on his time with the kids, both parents subscribed to "quality over quantity." Thus, when there was an airfare sale, Jim took Jack to Hawaii for his birthday. "It wasn't extreme—we don't buy Nintendos or anything, and the fares were so low, we couldn't afford not to."

Tori, who has mild cerebral palsy and ADD, was still in a regular classroom and continuing to struggle. All Ann wanted was for Tori to get the help she needed; she didn't care what label or diagnosis was given. Although the teacher, psychologist, and speech teacher all felt she needed resource specialist help, the resource specialist said Tori wasn't "bad enough." The Turners have requested a new IEP [Individualized Educational Plan] meeting. It wasn't even important to the Turners that Tori stay in regular education; Jim was ready to put her back in special education. In spite of her school problems, Tori has never had problems with her self-esteem. Ann attributed this to the fact that "there's no deception—she feels there's no deception about what's going on." When Tori asked why she couldn't write as well as her classmates, her mother explained it was probably because she has mild cerebral palsy, and she can't make her hands work the way she would like.

At home Tori needed minimal supervision. She was able to entertain herself for long periods of time, looking at books, and working on her math and spelling on the computer, which she enjoys. Ann made it a point to monitor Tori's work. Although Tori could dress herself, she had no concept of what goes together, and Ann usually had to oversee her choices. She could put her socks on, but was still unable to tie her shoes, so Ann bought the ones with velcro fasteners. When Tori left the front yard, she had to tell her mother, but Ann was adamant that she took no more time

to supervise than any other 10-year-old. There was also less medical supervision necessary than before, as Tori's cardiac situation had stabilized, and she was only being monitored by her pediatrician.

This visit to the Turners was summarized by the fieldworker as follows: "Easy child, mild delays, heart condition still unresolved but no impact on daily routine. Familial orientation, fundamentalist religious beliefs, mother sees child as a blessing and is happy to focus all her time and energy on the family."

Sustainability Complements Other Measures and Adds Value

The assessments, scales, questionnaires, and related information our project collected on children and families proved useful; they were associated in varying degrees to the four sustainability patterns (Multiply Troubled, Vulnerable but Struggling, Improving/Resilient, and Stable/Sustainable) that we found in our qualitative analysis. But a great deal of information about family sustainability was added, unique to the qualitative groups we formed. For example, Quality of Life scores based on individual reports by mothers accounted for about 25 percent of the variation in assignment of families to the four sustainability groups—a significant contribution, but leaving a good deal more to be understood through qualitative and contextual analysis of family sustainability. QOL has twelve subscales in the overall measure, and five of the twelve (marriage and family life, friendship, employment, home, and religion) were related to sustainability. Rather than based on crisis or unusual stress, perceptions of quality of life in these families were mediated by the overall daily routine and the degree to which it is sustainable. Assessments of caregivers' QOL combined with qualitative assessments of family context jointly enhance the understanding of the impact of disability on family life over either one separately (Bernheimer and Weisner n.d.).

Although it might be thought that the child's IQ and developmental assessments would be associated with family sustainability and well-being, this was not the case. This is an important nonrelationship, since these developmental scores are often used to assess functioning levels and severity of cognitive disability in children, with the inference that the lower the scores, the lower the family well-being as well. In our sample, however, families can have higher or lower sustainability independent of these normed child assessments. But the parental folk constructs of hassle show a different picture. Families with high hassle children *were* more likely to decline in sustainability over time, while

families with children with lower hassle and problems were more likely to move into the high sustainability category as the years went by. By the time the children with disabilities reached age eleven, troublesome child characteristics clearly were a hindrance to constructing a sustainable routine, just as easier child characteristics seemed to facilitate the process. In other words, there is evidence that as children get older, their *behavioral* characteristics are associated with parents' ability to sustain their family routine, but the child's *cognitive* abilities are largely unrelated. The reasons for this, based on the ethnographic data, appear to be that less child hassle and fewer child behavioral problems clearly increase the ability of parents and siblings to organize a daily routine that is lower in conflict, relatively predictable, and relatively more meaningful for all family members than is the case for high hassle and multiple-problem children. That is, those families have relatively greater well-being.

Sustainability among families with a child with disabilities shows that the construct can be reliably understood in context and rated across families. It suggests that the other complementary measures of life quality and child developmental status which we used also are useful in gaining a more holistic understanding of these families and children, and that sustainability adds significantly to our understanding of these other measures. A holistic anthropological perspective on family sustainability and well-being can, and I believe should be used wherever possible and appropriate, along with other methods and measures. In this way, the added value of including a deeper understanding of local context, cultural ecology, local idioms, and the meaning and direction of a well-lived life will enrich and extend other widely used indicators of well-being.

Notes

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1. The mean developmental quotient (a normed indicator of cognitive development) for the children in our sample was 72 when the children were age three to four, and ranged from 38 to 117. Though some children improved and others declined over time, this mean level for the sample remained about the same through age eleven.
2. Interviewer ratings of child hassle used a 9-point scale of hassles/problems in everyday life, rated by fieldworkers from 0 = low to 8 = high. Hassle includes: (1) behavioral hassles (e.g., tantrums), (2) medical hassles (e.g., seizures, use of multiple medications), and (3) communicative hassles (e.g., hard to understand, nonverbal, points, grunts).
3. A total unweighted sum score ranges from 40 to 200. Overall test-retest reliability is 0.64, with Cronbach alpha 0.92.
4. All case material has been disguised by changing names and nonessential information so that no family could be identified by using the information presented.

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